

**“YOU LOOK VERY WELL FOR A TRANSPLANT”:  
AUTOETHNOGRAPHIC NARRATIVE AND IDENTITY IN CHRONIC  
KIDNEY DISEASE, KIDNEY FAILURE AND THE LIFE POST-  
TRANSPLANT**

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## DECLARATION

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My doctoral research has been extremely important to me both personally and professionally. I could not have completed it without help and support:

- The Harry Crossley scholarship provided me with funds to attend a national conference (The Congress of the South African Renal Society, Durban, 2008) and an international conference (Qualitative Health Research Conference, Vancouver, 2009). These experiences helped me to develop extra dimensions to my research. In addition, I was able to buy books necessary for my studies – these were not available in South Africa – and an external hard drive, invaluable in backing up my research;
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## ABSTRACT

Despite the high prevalence of chronic kidney disease, renal narratives are under-reported. Much of what is written on kidney failure is written by health care professionals for health care professionals and about patients. While medical experts and health care practitioners have one type of knowledge, their patients have another type of knowledge acquired through their experience of their own condition. From within the disability and patients' rights movements urgent calls have been made for the authentic voices of disabled people and patients to be heard without the mediation of professional lenses. In response to this my dissertation combines personal and academic writing to explore my own experience of end-stage renal disease, dialysis, transplantation and the life after transplant.

I have used autoethnography as a methodology. Autoethnography is a relatively new, somewhat postmodern form of inquiry that developed from the reflexive turn in anthropology and narrative studies in the latter part of the twentieth century. It is very useful in writing about the experience of illness and reflecting on illness narratives because, in autoethnographic writing, the observer and observed, the narrator and narrated, insider and outsider are the same person. This allows scope for exploring the problematics of representation and for finding alternatives to already existing ways of telling certain stories.

Engaging with autoethnography's postmodern aspects has allowed me to conceptualize experiences that, until I undertook this research, I have never been able to articulate, because the traditional (static) illness narrative forms did not speak to my experience or my understanding of my condition. The central issue in my dissertation lies in the question: How do I tell the story of chronic illness once I have had an organ transplant? Flowing from this are a number of sub-issues: Can my story change? How do I describe myself: The well, the ill, the impaired, the disabled, the afflicted? Do I describe myself living in no man's land? In my narrative, do I oscillate between being well and ill, or do I occupy another territory entirely? And if I do, what is it?

My study shows that writing the story (or stories) of chronic kidney disease is complex, nuanced and dynamic and that, far from being an extended liminal experience, kidney disease is littoral. This distinction is important in coming to narrative terms with an identity that is not damaged so much as different.

Through this I hope to demonstrate to both outsiders and insiders, who often submit to narratives that are forced on them, that more satisfying alternatives can be found.

## OPSOMMING

Ondanks die hoë voorkomssyfer van chroniese nierkwale word nierverhale nie genoeg aangemeld nie. Die meerderheid van dit wat oor nierversaking geskryf word, word deur gesondheidsorgdeskundiges vir gesondheidsorgdeskundiges en oor pasiënte geskryf. Terwyl mediese deskundiges en gesondheidsorgpraktisyns een soort kennis het, het hulle pasiënte 'n ander soort kennis op grond van hulle ervaring van hulle eie toestande. Van binne die gestremdheid en pasiënteregte-bewegings het 'n dringende oproep weerklink vir die outentieke stemme van mense met gestremdhede en pasiënte om gehoor te word sonder die tussenkoms van professionele perspektiewe. In reaksie hierop kombineer my verhandeling persoonlike en akademiese beskrywings om my eie ervaring van eindstadium- nierkwale, dialise, oorplanting en die lewe na oorplanting te verken

Ek het outo-etnografie as metodologie gebruik. Outo-etnografie is 'n relatief nuwe, ietwat postmoderne vorm van ondersoek wat in die tweede deel van die twintigste eeu uit die refleksiewe wending in antropologie en narratiewe studies ontwikkel het. Dit is baie bruikbaar wanneer oor die belewenis van siekte en besinning oor siekte-narratiewe geskryf word aangesien die waarnemer en die waargeneemde, die verteller en dit wat vertel word, die ingewyde en die buitestander in outo-etnografiese skryfwerk dieselfde persoon is. Dit laat meer ruimte vir verkenning van die problematiek van voorstelling en vir die opspoor van alternatiewe vir reeds bestaande wyses om sekere stories te vertel.

My bemoeienis met postmoderne aspekte van outo-etnografie het dit vir my moontlik gemaak om ervaringe wat ek tot en met hierdie navorsing nooit kon artikuleer nie, te konseptualiseer, aangesien die tradisionele (statiese) vorme van siekte-narratiewe nie tot my ervaring of my begrip van my toestand spreek het nie. 'Hoe vertel ek die storie van chroniese siekte nadat ek 'n orgaanoorplanting gehad het?' is 'n sentrale vraagstuk in my verhandeling. Hieruit spruit 'n aantal newevraagstukke voort: Kan my storie verander? Hoe beskryf ek myself: Die gesonde persoon, die sieke, die verswakte, die gestremde, die aangetaste? Hoe beskryf ek myself wat in 'n niemandsland woon? Fluktueer ek in my narratief tussen gesond wees en siek wees of betrek ek 'n geheel ander gebied? En indien wel, wat is dit?

My studie toon dat, om die storie (of stories) van chroniese niersiekte te skryf, kompleks, genuanseerd en dinamies is en dat niersiekte glad nie 'n uitgebreide liminale ervaring is nie, maar eerder littoraal is. Dit is belangrik wanneer daar tot 'n narratiewe verstandhouding gekom moet word met 'n identiteit wat nie soseer beskadig is nie, maar eerder anders.

Hierdeur hoop ek om aan beide buitelanders en ingewydes, wat dikwels voor narratiewe wat op hulle afgedwing word, moet buig, te wys dat daar meer bevredigende alternatiewe gekry kan word.

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## FOREWORD

A time comes when one can tell a story. It may be immediately after an event or it may take a long time for the time to be right. In my case it took me nearly 20 years and a series of unfortunate events to be able to start telling the story of my experience of Chronic Kidney Disease (CKD), End-Stage Renal Disease (ESRD), dialysis, transplantation and the life afterwards. Something changed to allow me to do this. What changed? Possibly me. Possibly having sufficient distance from some of the events allowed me to articulate a version of what happened. Possibly time and experience allowed an older me to have some points of reference to be able to explain or narrate some parts of the story.

But I think it was largely fury. This is what set it off. This foreword is not the story itself, but the preamble to it and simultaneously, ironically enough, the sequel. A story is seldom linear. Like life, it is messy and recursive. Its end is in its beginning and vice versa. Its end and beginning might crop up in a variety of other places too. This is what I experienced when I wrote my story. I always seemed to be starting. And starting again. And again. But let us not get ahead of ourselves and instead sustain that illusion of narrative, that one thing happened after the other. Let us pretend this really is the beginning, because I need to show you where the story started for me. And it started long after I thought it had ended.

To start this story properly I need to go back to an event in 2006, sixteen years after my transplant and 37 years after my kidneys were damaged by Haemolytic Uremic Syndrome (HUS). It happened like this.

I had taken out a mortgage on my house and had been offered health insurance as part of the agreement, which included property insurance and other things. To obtain the insurance, which would have given me financial cover should I suffer from illness or injury, I had to undergo a series of blood tests.

Friends my age, who have always had normally good health, are now being treated for spastic colon, hypertension and diabetes. I don't suffer from these. I'm healthier than they are and less of a risk. I don't drink or smoke or indulge in reckless behaviour. I'm a law-abiding driver. My family doesn't have a history of cancer or other diseases of lifestyle. I am a good candidate for insurance – or so I thought.

The nature of these tests was not revealed to me, although I asked my broker what they entailed. I asked if I needed to fast before them and was told I did not. I assumed the tests to be some type of HIV test or a cancer marker test to determine risk. The results were not what the insurance company expected, so I was asked to retake the tests. My head spinning from fear and disbelief I returned to the pathology lab. The new tests confirmed that I was suffering from several disastrous (but unnamed) ailments and should seek medical assistance as soon as possible.

No one would tell me anything. They would not tell me what was wrong with my blood tests. They would not tell me if I were in immediate danger. All they would tell me was that I didn't qualify for health insurance. I was terrified. As an organ transplant recipient, the last thing you want to hear is that there is something wrong with your blood results – something so awful no one will discuss it with you or allow you any health insurance. Kidney function is monitored through serum creatinine. Blood tests tell you how well your transplanted kidney is functioning.

Eventually I visited my doctor, who informed me that according to the insurance company I was suffering from severe diabetes, drastically elevated cholesterol and a malfunctioning liver. I retook the tests at my own expense and found that, when I fasted as I was meant to do for 12 hours before them, my results were perfectly normal, even for a “normal” person.

While my terror abated, my fury grew to such massive proportions that I found myself unable to speak. I could think of nothing other than the monstrous trick that had been played on me, how I'd been led to believe that I was dreadfully ill, but actually was quite well, how I was still not allowed any health insurance, despite my informing the insurance company about the error with the results. I was convinced that the real reason I had been treated so was because they did not want to cover an organ transplant recipient – that I would be considered high risk, but they had disguised this by sabotaging my blood results, because otherwise their course of action would be discrimination in legal terms. The last straw was when they offered me life insurance instead. I have no dependants.

The only way I could relieve any of the pressure that was building up inside me was by writing compulsively and at length about something I had never before been able to articulate: how I experienced having had a transplant and what effect this had on my sense of myself, how I tended to see things through that identity, how I suspected that that identity was all others ever saw of me and, most disturbingly, how I did my best to keep that identity a secret. The insurance company that originally offered me the health insurance had not been aware of my medical condition when they offered it, because I had never in all those years discussed it or

mentioned it to my broker. Had they known, I doubt they would have offered me any. They found out only when I completed my forms.

The pent-up feelings of nearly twenty years gushed out of my pen like the breaking of a dam or levee. I wrote about things I never knew I felt. It was as if I had found a secret self hidden inside me who had lived and experienced awful things without my knowledge as I went calmly about my day-to-day business for years. This being had escaped, had found a voice and was never going to be silenced again.

I never found out to what extent my transplant had influenced their decision not to give me any health insurance. In time my focus shifted to expressing what I felt about my condition and its effect on my life. I declined the life insurance, as I felt I had paid quite enough for having had an organ transplant.

## **CHAPTER 1: INTRODUCTION - BORDERLANDS, THRESHOLDS AND THE LANDSCAPE OF LIFE POST-TRANSPLANT**

### **1.1 Introductory statement about the writing style**

At the heart of the questions I raise in this dissertation is the question of how particular stories are told. The research design is autoethnography, which allows me to narrate my own experience of chronic kidney failure, dialysis, transplantation and life afterwards. This will be carried out against a backdrop of illness narratives in general and renal-related narratives in particular to provide a context and, to some extent, a dialogue between my narrative and the others (Frank, 2010). While the autoethnography is central to the dissertation, it needs to be seen in the context of other types of illness narrative and will, indeed, talk to these narratives as it progresses.

In my research I have used different types of writing as part of my autoethnographic process to examine and (de)construct the complex narrative of chronic illness and life post-transplant. Doing this is not, of course, unproblematic and I examine the issues around this methodology during the course of my dissertation. To remain true to the epistemological aims of autoethnography I have adopted a more personal style of writing from the beginning of my dissertation. This way I hope to avoid privileging the academic episteme over the personal. I have even framed my dissertation with personal narrative – the foreword and the last section of the conclusion. Both these pieces of narrative are essential for understanding my research journey and my story, but in allowing them to frame the dissertation I symbolically give them another sort of status: the first and last word. My story existed before my research, although it changed in the course of it. After my research is finished, my story shall continue.

My dissertation is not written in a conventionally academic form. Instead I have played with the traditional structure of a dissertation in order to blend or blur two genres: qualitative health research writing and life story writing. I discuss my theoretical position in more detail in Chapters 2 and Chapter 3. In brief, my intention is to create a third type of writing that can express both academic and personal concerns, and can depict, describe and embody as accurately as possible a phenomenological research project about the experiences of an individual life.

In keeping with many of the philosophical concerns of postmodern<sup>1</sup> research or research in a postmodern age, telling one's own story as one's research can allow a previously silenced or diminished subject a voice and power. Writing can be a means to knowledge, not an end. Writing is part of an on-going dialogue between writer and reader, writer and text, reader and text, and writer/reader and world. Reflexivity and treating the research explicitly as an iterative process is part of this. I have also chosen to refer to myself in the first person from the beginning for that reason.

## 1.2 Background

In 1997, at a scholarship interview, a medical doctor on the panel told me, "You look very well for a transplant". I was filled with conflicting emotions. I was glad I looked well, but I was perturbed by two things: the underlying assumption that an organ transplant recipient should not look well and the realisation that I was seen as a medical procedure, not a person. That long-ago statement that so unsettled me, that wormed its way into my psyche, was, as I came to see, both true and false at the same time, both relevant and irrelevant. And yet I could not provide a counter-narrative (Nelson, 2001) that did not reduce me to a medicalised category of information or a malfunctioning body (Cook, 1996; McDougall, 2006; Shildrick, 2002).

That throw-away remark by the doctor haunted me and seemed to follow me through life: the idea that I *looked* well, although I was clearly not meant to, and that by implication I should not, could not *be* well after having a transplant and that, having had a transplant, I could only ever aspire to be a transplant, not a person. Until then I had to a large extent seen myself as healthy after my kidney transplant. Now I felt as if my status had changed to something inferior. I left the scholarship interview feeling as if I had become much less than when I had arrived.

Thomson (1997) explains that valorisation of uniformity and unity creates the binary of normal/abnormal. This results in "freak discourse" (Thomson, 1997, p. 29). So powerful is this discourse, as powerful as medical discourse and often deeply connected to it, that it would be years before I could see that "[t]he fissures, breaks, contradictions and indeed unexpected continuities in the received meaning of the monstrous are not then problems to be resolved, but opportunities to reconfigure first impressions" (Shildrick, 2002, p. 27).

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<sup>1</sup> I use the term "postmodern" advisedly here and throughout my dissertation, aware that it exists as a concept in different forms across many disciplines. My intentions in using it as a lens are (metaphorically) post-colonial and transformative – I want to destabilise entrenched power structures and to restore some power and voice to vulnerable and disenfranchised communities. Narrative as a way of knowing remains to some extent displaced in research. My research challenges that, as it challenges the idea of an objective reality and unsettles traditional categories and genres. Through this I hope not to find new answers, but instead to open up new questions, to unsettle and to perturb.

Because I could not yet see this in 1997, I disappeared. Disappearance (Leder, 1990) is when the body causes one shame and becomes a type of visible and monstrous symbol of that shame. In doing this, one is rendered invisible as an individual and becomes a type. I fled from my diminished status and hid. I had grown up in Johannesburg, but had recently moved to the other side of the country. Here I knew no one and no one knew I had had a transplant (unless I trusted them enough to tell them). I went to clinic visits every three months, then every six months and finally once a year. That was the only time I had anything to do with other transplantees or kidney specialists.

In Johannesburg I had been in regular contact with other transplantees, had helped promote organ donation, had advised people who were waiting for a transplant, had even been part of a patients' group. Now, in the Cape, I didn't join any groups, didn't raise any awareness, didn't speak to other people with the same condition as I had. I learned how to pass (Goffman, 1963/1990) as healthy and normal and everything was perfect until 2006, when the insurance company (with which I started this story in the Foreword) denied me health cover and something in my psyche imploded. And so my research journey began. The Foreword to the dissertation outlines what happened and provides a way into my research for the reader, as it did for me.

This research initially resulted in a document called "You look very well for a transplant: scenes from re(n)al life" (Richards, 2006). Its objective was to capture in article form an individual experience of surviving a life-long, chronic illness, having a kidney transplant and becoming well enough to lead a "normal life". As I proceeded with my early drafts of the article, I found myself questioning what was normal about my new life and indeed examining what constituted that life. At first I meant to show how others viewed me, but soon I came to see it was really about how I viewed myself and how I had constructed my identity post-transplant.

I discovered that the narrative kept changing shape and that it produced certain types of metaphors. It was extremely difficult to write because it was so personal and so complex. I learned a great deal about my self-perception and realised there was a lot more to learn. I also found that narrative does not simply describe. It interprets. It inscribes. It translates. It transforms. It controls. I wanted to pursue this narrative and to see where it led me. I began my doctoral research to explore this further, because I needed to provide myself with a better context against which to consider my narrative and to be able to theorise what I was seeing.

In writing my story those first times, between 2006 and 2010, I saw that it did not fit into the patterns I had seen of renal narratives (Cojocaru, 2007; Etherington, 1991; Hermans, 2006). Was it unique? I wasn't sure. But I knew it was mine at last. I also saw that my story needed to



be partly personal narrative and partly academic writing. For me to understand, I need to use an intellectual lens as well as an intuitive one. I had wanted my research to develop rhizomatically (Honan, 2006; Richardson & St. Pierre, 2005) – to produce a theory that develops from events. However, I was forced to see that I understood my events in the light of pre-existing theory too. I have, however, discovered that I need to unpack my life philosophy or philosophies to be able to talk about myself (or my self); hence I wrote this dissertation instead of only keeping a journal.

Before I discuss the focal area of my research, I shall outline some of the concepts that both challenged and informed the development of my ideas. One of the questions raised by qualitative research is: What constitutes evidence? One of the resulting questions in researching subjective experience is: Who creates it, defines it or judges it? (Miller & Crabtree, 2005, p. 613). Writers across disciplines are questioning epistemologies and their impact on the people who are being researched (Richards, 2008). This has led to different types of resistance and subversion by the subjects of research as well as by some researchers.

### **1.3 Rationale: Challenges in writing about illness**

Representation is of immense concern in postmodern academia and in qualitative health research. In a postmodern age it is difficult to accept the idea of a transcendent truth or a purely objective writer or reader. In many ways, we are at present “between stories” (Denzin & Lincoln, 1998b, p. 425). How things are represented and who represents them are crucial to understanding what one is actually seeing and this has implications for the thing being represented as well as for the representer. Every narrator is embedded in a cultural context (or contexts) and is part of a discourse, and so objective distance is never attainable in a human story. Representation of others can all too easily lead to their being colonised and objectified, being reduced to one part of a binary.

Binaries do not accurately capture the lives of many of us who are (or were) ill or disabled – possibly none of us. For instance, as a dialysis patient, a time when I was both ill and disabled, I was not able to run marathons, but I was able to complete my Honours degree. So I was not disabled in every way. I was ill, but not as ill as I had been the year before dialysis, when I was barely able to manage one undergraduate course. I am quite well now, but not apparently well enough to qualify for certain scholarships or certain kinds of health insurance. Even the “well” are not always well. In discussing health and illness I find one needs a third option, an

alternative state, that may share qualities with “well” and “ill”, but that has qualities of its own too. Garber refers to this as a “third space” (1997); Glissant refers to it as *métissage* (2002).<sup>2</sup>

I discuss certain aspects of illness writing and research in Chapter 2 and telling stories in the third space in Chapter 3. However, in order to provide context for my own research I briefly outline some of the key issues below.

### *1.3.1 The medicalisation of vulnerability*

I tried to write my story in 1991 when I had my transplant, but could not because I was constrained by a normalising, medical narrative that was not my story. I could not get past the facts and figures, and so could provide nothing more than a tabulation of dates, pills and blood results to explain my experience. This medicalisation of narrative is extremely pervasive for reasons I outline below.

Although medical science can prolong life and cure many ills, it cannot yet grant us complete invulnerability or immortality. As Sontag (1978, p. 3) puts it,

Everyone ... holds dual citizenship, in the kingdom of the well and in the kingdom of the sick. Although we all prefer to use only the good passport, sooner or later each of us is obliged, at least for a spell, to identify ourselves as citizens of that other place.

Despite this, or perhaps because of it, Western culture tends to construct illness and disability in terms that are themselves disabling and “othering” (Frank, 1995; K & Duncan, 2006; Kleinman, 1988; Marks, 1999; McDougall, 2006; Sontag, 1978; Vehmas, Kristiansen & Shakespeare, 2009). This is because “[b]odily dysfunction is perhaps the most common threat to the appealing belief that one controls one’s destiny” (Couser, 1997, p. 9). Members of the dominant group can control, legitimate and normalise the lives of those who are different by writing stories about them. These types of narrative control and explain, as well as reconstruct identities to make the “deviant” more acceptable to the “norm”. These narratives tend to marginalise their subjects. One of the most common ways in which this happens to ill or disabled people is through depersonalising and generalising medical narratives that allow doctors to “reinterpret patients’ pasts and literally pre-script their futures” (Couser, 1997, p. 10).

The biomedical perspective reduces the ill or disabled body to categories of knowledge (Cook, 1996; Shildrick, 2002). Disabled (and ill) people are often “reduced to the status of malfunctioning bodies” and viewed as “lacking capacity to put forward their point of view”

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<sup>2</sup> Garber is addressing gender binaries, while Glissant is concerned with postcolonial identities. Nonetheless, both writers are attempting to find spaces of possibility that can accommodate identities that may not completely fit the binaries that are available. Perhaps this third space can help us to reconsider the often accepted binaries.

(McDougall, 2006, p. 395). In addition, bodily dysfunction “is complex and demands a personal – and not always comfortable – response.... It seems, often, to exist beyond a barrier of thinking and seeing that encloses disabled people in silence and obscurity” (McDougall, Swartz, & Van der Merwe, 2006, p. ix). This is a problem for two main reasons. Not only can the biomedical perspective reduce people to objects and silence them, but it cannot yield certain types of information about the lived experience of illness or disablement that may prove extremely important in treating or supporting people. Moreover, there may not be space in the biomedical approach for the voices of the people experiencing medical conditions to be heard. After all, “the ability to *relate* one’s story depends on there being a *relationship* in which that story can be received, recognized, and responded to” (Carson, 2002, p. 175).

### 1.3.2 *The need for an insider voice*

Because of this, the insider perspective on illness is so important:

Until the academic discourse of medicine is extended beyond the languages of molecules and drugs to include the language of experience and meanings...medical science will reinforce the profession’s resistance to the problems of illness rather than contributing to broadening its vision. Research that avoids the human side of disorder places the profession and its practitioners in the iron chains of restricted knowledge. (Kleinman, 1988, p. 266)

This is becoming increasingly widely recognised, although not everyone would go so far as to say, “We recognize that individual sick persons and their families are the occasions for vision and insight for us all” (Charon & Montello, 2002, p. xii). Nonetheless, medical practitioners and researchers need to remember the human element of illness and disability because, “[a]lthough illness is, indeed, a biological and material phenomenon, the human response to it is neither biologically determined nor arithmetical” (Charon & Montello, 2002, p. viii).

For reasons both ethical and practical, the subject/object dynamic is of particular concern in qualitative studies of illness and disability. If one represents another human being, particularly one who is already marginalised by society, what is one doing to them? Representation can lead all too easily to objectification and reification. Representation can erase uniqueness and allow generalisation. It can emphasise similarity or difference and, by so doing, elide complexities.

Qualitative researchers tend to emphasise the importance of the insider’s view and experience in research into medical conditions (Charon & Montello, 2002; Frank, 1995; Garden, 2010; Garro & Mattingly, 2000; K & Duncan, 2006; Kleinman, 1988; Marks, 1999; Sullivan, 1986). While medical experts and health care practitioners bring one type of knowledge to their

patients, their patients bring another type of knowledge through their experience of their own condition.

Medical practice has changed since the day of Parsons's (1951) doctor-patient dyad, where the patient was passive and childlike, and the doctor the one who asked the questions and controlled the conversation. Carson, a medical ethicist, describes the necessity of a dialogical relationship between doctor and patient for treatment that is both ethical and medical, and adds that such communications "must strive to be radically egalitarian" (2002, p. 175). But is this possible? Jones (2010) asserts that doctor-patient dialogical narrative ethics should aim to be as non-hierarchical as possible, although she points out that even in Carson's work the doctor is nonetheless still privileged.

In response to these types of concerns, researchers have tried various social sciences approaches to explore the qualitative dimension of health care and the experience of illness. Nonetheless, in studies where researchers have involved patients, the relationship can sometimes be as non-egalitarian as with a medical doctor. These sorts of dialogues are not dialogical in the sense that each conversational partner speaks an equal amount and their words are equally valued. The researchers tend to decide what shall be researched and how. They ask the questions. They choose what to include in their articles. In some interviews and participatory action research, stories are part of a dialogue, but the participants might have varying social statuses (Allen & Hutchinson, 2009; Fontana & Frey, 2005; Hertz, 2006). This is of great concern in qualitative health research, where despite the best intentions of researchers, the people whose experiences are studied can all too easily become subjects or even objects, despite many researchers' intentions of helping them be heard.

### *1.3.3 Illness narrative and the need for a third space*

Illness narrative is a way of writing about illness that captures the insider's experience without the mediation of formal research (Kleinman, 1988). Such narratives can take many forms, but they are all told by people who have experienced illness themselves. Examples include Bauby (1997), Broyard (1993), Cojocar (2007), Grealy (1994), Hornbacher (1999), Klug and Jackson (2004), and Woolf (1930/2002). Their audiences include others with the same condition, family members of people with a condition, care providers, researchers and other interested members of the public. They can act as a form of advocacy and as a source of information about the experience. They can do more than this too.

Many illness narratives "make sense" of the fragmented and fragmenting nature of illness as an experience (Mattingly & Garro, 1994, p. 771). Illness has been seen as a "series of disconnected shocks brought under control by narrative" (Broyard, 1993, p. 19). Through

stories people can make sense of a changed identity, piece back together a life and gain control. Sometimes this is known as therapeutic emplotment (Mattingly, 1994). “Making sense” and “controlling” are forceful terms that seem to suggest that some sort of struggle and resistance will be involved.

More optimistically Brody (2003), like Bury (1982), finds that telling and hearing stories of chronic illness can be healing, allowing the teller to grieve an old story and write a new one. In a sense, if one is using a story to study an experience and gain an understanding of it, one is doing a form of action research, because one is making the story and living it as well as relating it. In addition to this, narrators want to make readers more aware of their condition and to transform the readers’ response to it (Garro, 1994).

Paying narrative attention to the experience of illness “forces us to confront the problem of meaning and the human affinity to endow the human experience with meaning” (Garro & Mattingly, 2000, p. 269). In other words, a story of illness can be two things at once (Frank, 1995):

- 1) A personal story, for instance, that of reconstructing a damaged self. Sometimes this entails making a new self that one can feel proud of, although it is different from the self one thought one was going to be; and
- 2) A social one. We reconstruct ourselves individually, but also in terms of the communities in which we live or to which we return after illness.

Illness narratives – particularly those that have autoethnographic qualities – are more than this, however. An illness narrative is not just the story of illness; it is “a story of a life altered by illness” (Garro, 1992, p.101). This distinction is essential. A story of illness reifies and generalises (as medical discourse does), while a story of a life altered by illness retains the individual human experience, allowing for both uniqueness and generalisability. The complexity of that life and the individual self’s experiences have not been denied or suppressed. Illness narratives can help the story-teller ascribe meaning to the illness that can have significance for other people either suffering from the same illness or knowing people who do (Couser, 1997; Frank, 1995; Kleinman, 1988). Such stories express the interplay of body, mind and culture (Couser, 1997). These narratives act as testimony for people and thereby serve an ethical function for society: “Storytelling is *for* an other just as much as it is for oneself” (Frank, 1995, p. 17). They are not, however, unproblematic; I return to this in Chapter 2. Some stories have yet to be told. The story of becoming well after a life-long kidney disease is one of them.

#### 1.3.4 *Liminality in illness*

Telling a story can create a type of metatextual landscape. Stories concern place, time and space, people and relationships (Clandinin, 2002). That storied landscape, however, is an in-between realm. It is both in time and out of it. It is both here and there in terms of place, both inside and outside together, both nowhere and somewhere, always being, always becoming, alongside ceasing to be and not being. A narrative can be seen as a liminal space, a means of getting from an old identity to a new one (Sandelowski, 1991). Perhaps one must consider that illness narratives could instead be not mimetic, but ritual objects that stand in for something absent and that their performative nature enacts what is wished for or desired: order, clarity, or closure.

Liminality is a ritual state that allows a person to move from one social condition to another, through an intermodality of socially imposed structure and antistructure (Turner, 1969; Van Gennep, 1960). It is a social construct that allows us to understand change. It is not a naturally occurring phenomenon. On the contrary, it is something people impose on naturally occurring phenomena or on changes in status within a community.

Sometimes life after catastrophic illness is described as a type of liminal state. According to Van Gennep (1960), liminality is a temporary state in which you withdraw from society, undergo purification and then reintegrate into society in a new role. This reintegration is often seen as a form of rebirth. Illness often requires that a person be isolated from society to be healed. They must subsequently return to society, improved by their experiences, literally and figuratively to fulfil a new role. This is why illness can be seen as a liminal condition, although not a ritual one.

However, the liminal state in catastrophic illness, such as cancer or organ failure, may not be temporary. Instead, people who have experienced catastrophic illness may continue to live in a state of sustained (Little, Jordens, Paul, Montgomery & Phillipson, 1998) or persistent (Crowley-Matoka, 2005) liminality, sometimes for the rest of their lives. Rather than re-emerging into “a fully ‘normal’ life of health and productivity”, such people often experience “living between the states of ‘health’ and ‘illness’,” (Crowley-Matoka, 2005, p. 7). Kleinman describes this in-betweenness as a frightening no man’s land (1988, p. 181).

Those of us who have had transplants are, and yet are not, seen as different from the communities in which we live. Sontag spoke of the domains of the well and the ill as being two domains so separate that they required, metaphorically, different passports (Sontag, 1978). Where does that leave us? Frank describes people who have recovered from a dread disease, but who still require long-term treatment, as belonging to “remission society” (1995, p. 8). This

suggests that the larger community in which everyone lives encapsulates a society, possibly “secret”, in which some of us function too. But we members always know each other and, when we meet, we communicate on a different level because we know each others’ stories too.

Recursiveness and persistent liminality are linked. You cannot have one without the other. This may be why so many stories about liminality are ghost stories of one or other sort. Ghosts keep returning to the scene of their deaths or of their crimes. This is what haunting is. They have not crossed over to the other side. They are still here when they ought not to be. Usually in stories they are exorcised, banished, laid to rest. End of story.

But we are not ghosts and our stories are not lived in books. And yet some of us, especially those of us who have been (or still are) seriously chronically ill, continue to hover between worlds, those of the living and the dead, the well and the ill, the able-bodied and the disabled, the normal and the abnormal. We cannot comfortably occupy either part of the binaries. It is as if our identities have become not in-between so much as doubled. This is why I find I need another term than liminality to describe my condition post-transplant.

### *1.3.5 Littorality and the third space*

In illness, part of the difficulty is that we might value a ritual, but illness is not a ritual event. Nor is it tidy and bounded. The boundaries blur between states we like to keep separate (health/illness, patient/non-patient, life/death, etc.). Ritual might be part of social life and on some level we might require a ritual to allow us to re-enter society, but our very condition might prevent that ritual from being completed or even from taking place at all. Alternately, a ritual superficially imposed over a persistently liminal condition runs the risk not of providing closure, but of foreclosing (taking away your right of redeeming), because such “closure” is artificial. The feeling of in-betweenness is real. One is aware of not properly belonging to one or other state, like a person who has dual citizenship, but who pines for and visits “the old country”, while trying to adjust to the new one, but never truly feeling at home.

My experience of a life-long illness can be seen as one of persistent liminality (Crowley-Matoka, 2005) – or of periods of persistent liminality. These periods overlap, like Derrida’s palimpsests (Derrida, 1978). I cannot see one without having to look through another. My state of liminality on dialysis can only be read through my state of liminality in ESRD or even post-transplant. My state of liminality post-transplant can only be understood in the light of the others. I am well and ill simultaneously and in different ways. Sometimes the different narratives of health/illness obscure each other.



Murray refers to this as “the doubleness common to all disability” (2006, p. 18), explaining that this is troubling to people because it exposes the “multiple nature of all humanity”. While this may be troubling to the non-disabled or the non-ill, I have noticed that it remains troubling to disabled and ill people as well. At any rate it does for me. I like to know where I am and society has not really provided me with a useful category for this, at least not a category that reflects well (so to speak) on me.

Metaphorically I was issued with new documents when I had my transplant. I know enough and have seen enough of post-transplant life to know how easily those documents can be revoked because of rejection, organ failure or complications arising from the immunosuppressants we take to prevent loss of our transplanted organs. These documents might be considered a passport by some who would prefer to see one now as a citizen of the “kingdom of the well”, but really they are more like a visa. I have a residence permit in the “kingdom of the well”, not citizenship. And a visa can be revoked for the slightest of reasons. A person with an extended visa or a residence permit belongs and yet does not belong. Such people do not have the rights a citizen has. But they want to be naturalised. So they learn the language, the customs, the way to dress. They follow these very closely, slavishly, in fact. They dare not deviate. They do not want to be found out to be alien and sent home. Is this really liminality?

I know how to pass in my new country. I know how to look well. But what if I am not living where I expected to live, either in the kingdom of the well or the kingdom of the ill (Sontag, 1978)? What if I am living somewhere else entirely? I find the idea of occupying another space more empowering. When I began writing my renal narratives, I recognised liminality and wanted to end it through an acceptable plot. I came to see that forcing this type of plot onto my narratives prevented me from exploring my in-between condition and understanding it better. Despite myself, I was still adapting to a central, dominant narrative of “recovery” and health, whether I saw myself as passing as healthy or actually being healthy. I wondered if I was not simply marginalised, occupying a peripheral position near a border between well and ill. But this did not quite seem to fit either.

If power can be said to reside in the centre, then its absence resides on the peripheries. The periphery is populated by the Other, whose life is primarily seen in terms of what it is not – “not like us”. This existence is characterised by “lack, fragmentation, partiality, imitativeness and unfulfillment” (Pratt, 2002, p. 31). The perceived liminality of illness can be seen in this way. Carson (2002, p. 180), for instance, sees it as “a place of ambiguity and anxiety”, something to be controlled and overcome, to be given a shape to through relationships, so that one can get



back on course. That may be what the periphery looks like to those in the centre. But what does it look like to those on the edge (so to speak)?

The peripheral intellectual inhabits “the space between” (Santiago, in Pratt, 2002, p. 32). This can allow people to reflect on how the centre and peripheries interact and to set change in motion. “Challenging the centre’s self-endowed interpretive monopoly involves asserting difference against false claims of sameness” (Pratt, 2002, p. 34). Perhaps by following the stories of displaced people and seeing how they experience their identities in the space between, one may find ways of escaping dominant ideologies. I was amused to see Elisabeth Mudimbe-Boyi, a post-colonial writer, refer to such people as “displaced or transplanted”, although she was not referring to organ transplants at all (Mudimbe-Boyi, 2002, p. xii). Like Glissant (2002), Lionnet (1989) and Spivak (1988), other post-colonial writers, her intention was to make space for new identities for such displaced people, identities that do not merely derive from colonial pasts, existing as a derivative patchwork of other people’s cultures, but instead new and vital identities with inherent value. Her work and that of other postcolonial writers got me thinking about the curious position of one who has had an organ transplant and made me start to understand that my particular sort of in-betweenness might have some advantages.

As I came to terms with my disablement, my abnormality, my post-transplant identity, I came to see that my shame and my disappearance were the result of my perception of myself in terms of the well/ill binary. I had previously persuaded myself that I was “normal” and the reminders that I was not (the health insurance debacle, the scholarship fiasco) caused me crises because they rocked my sense of myself to the core. The self is contained and its boundaries secured by separation from the “other”: “And yet time and again the monstrous cannot be confined to the place of the other; it is not simply alien, but arouses the always contradictory responses of denial *and* recognition, disgust *and* empathy, exclusion *and* identification” (Shildrick, 2002, p. 17). If this was the cause of my dismay, I needed to study it. If I was simultaneously both well and ill, able-bodied and disabled, normal and abnormal, I could not afford to deny parts of myself.

I had to see that I did not belong to part of a binary (well/ill or normal/abnormal). But I could find this only by writing (Jones, 2005; Richardson & St. Pierre, 2005). By writing about my experiences and my condition I came to see that the space I inhabit may well be seen as liminal by some, but the liminality is not likely to be resolved. It is a type of third space (Garber, 1997), an alternative to binaries of well/ill or normal/abnormal. I have lived with in-betweenness for so long that I have realised while writing about it that for the most part I am not uncomfortable with it. On the contrary, it is who I am. I came to see, moreover, that what I

had understood as in-betweenness had other dimensions that took it beyond being somewhere on a continuum between binaries.

I prefer to name this condition a littoral state or zone. A literal example of a littoral zone is the sea shore, where the waves roll in and out over the sand, so the edge of the sea and the place where the land starts changes all the time. It is a messy area that contains flotsam and jetsam, tracks that are made and erased and over-written. It is neither sea nor land. It is something else entirely and always dynamic and shifting. It is a blurred boundary. It can be a threshold to another realm, but it can also exist as a zone in itself. My lifetime experience of chronic illness more closely approximates this state than a state of liminality.

#### **1.4 One form of littorality: Kidney disease and how we write about it**

Kidney failure, dialysis and transplantation are widespread phenomena. For instance, the most recent large-scale research shows that annually there are now approximately 100,900 organ transplants done worldwide, of which approximately 69,300 are kidney transplants (WHO Global observatory on donation and transplantation, 2010). And yet there is no term for “life after kidney transplantation”. “Remission” – a term borrowed from cancer treatment – is the closest to be found. A possible reason is that kidney failure has a different and, in many ways, less symbolically resonant cultural significance than diseases that have their own “vocabularies”, such as cancer, heart failure or AIDS. Having borrowed terms to describe one’s condition affects the lenses through which one understands and writes about oneself.

Some diseases, such as cancer and AIDS, have a social identity and metaphorical resonance (Couser, 1997; Sontag, 1978) that mark the sufferer permanently. Kidney failure does not carry the same burden of meaning. Indeed there is little symbolic value to kidney failure. This may in part account for the small number of published narratives on the subject. If an illness carries a metaphorical resonance, people who do not suffer from it can identify with its concerns. If it does not, they cannot so easily do so. Kidney failure is often a greater silent killer than cancer and has the same post-transplant success/failure rate as many cancers have after radiation therapy, but its name does not strike the same chord of fear as cancer’s does (Ries et al., in National Kidney Disease Education Program, 2005). As a result kidney failure is rendered less visible in society than cancer and therefore has an additional challenge with which to contend.

Over the last 25 years transplants have become more successful and are lasting longer. As far back as 1989 (two years before my own transplant) transplant recipients were experiencing frustration because they did not know how to define themselves. Their transplants were

successful, but they had long-term medical complications, side-effects and readjustment problems of finding meaningful employment and returning to society (Reimer, 1989). How might people in such circumstances describe their lives? Are you well or are you ill – or are you something else?

Transplantation is different from many other medical procedures, because it does not treat by recovery, but by replacement (Reimer, 1989). Transplant surgery is the focus of most people's understanding of transplantation, because it is so dramatic (Clapp & Clouse, 1989; Reimer, 1989), but for transplant recipients that is only the continuation of life-long medical care and the beginning of a different type of vulnerability. A transplant can suddenly fail or die and the recipient will be left facing organ failure, life-support and possible death. Because of this, we need more research on the different types and stages of in-betweenness after kidney transplant.

Most research about organ transplantation is medical. Some writing is by people who have undergone transplants themselves. These narratives tend to have “comic plots” that end with them on the brink of, or enjoying, a second chance at life (Hermans, 2006; Klug & Jackson, 2004). This type of narrative has conflict, but it is resolved and the ending is happy, as opposed to a “tragic plot”, where conflict is not always resolved and the ending is sad. These “comic plot” narratives tend to read like ‘how to have a happy transplant’ guides that justify suffering and explain a second chance at life. They are not very different from the medical narratives in that they tend to have a generalising, linear approach to organ transplantation, are focused on medical symptoms and pathology, and elide philosophical and ethical complexity. They conceal information in order to conform to certain expectations of society (Frank, 2010). A number of key questions remain unasked in these narratives. I aim to address some of them in my autoethnographic study of my own experience of kidney disease and its therapies.

There is surprisingly little written about kidney disease by people who have experienced it (Nicholas, Picone & Selkirk, 2011; Richards, 2008). This is even more the case for stories of childhood experience of kidney disease (Darbyshire, Oster & Henning, 2006; Nicholas et al., 2011). And yet these stories are so important to people living with the condition. Narratives can help children through kidney disease by allowing them to express their experiences and fears, to deal with them and to share them with care-providers (Nicholas et al., 2011). Not only that, but these stories are also important to care-providers, enabling them to help better, so much so that some researchers insist that paediatric research and health care ought to include patients' points of view (Horstman, Aldiss, Richardson & Gibson, 2008; Sartain, Clark & Heyman, 2000).

In Chapter 2 I discuss the literature in the field of kidney disease by both researchers and people writing their own stories about it. What I shall demonstrate is that these two groups of writers very seldom overlap and that each group to some extent conforms to conventional ways of talking about kidney disease and its treatments that can limit the insights into the condition. There is a gradually developing trend in renal writing to include patients' voices (Allen & Hutchinson, 2009; Nicholas et al., 2011). I wanted to go beyond that, as both patient and researcher, and to problematise issues of voice, narrative ordering and authority in renal narratives.

### **1.5 The focal issue of my doctoral research**

The focus of my dissertation concerns the problematic of writing about my own experience of kidney failure, dialysis, transplantation and life afterwards. I have done this through autoethnography, a relatively new form of inquiry that developed from the reflexive turn in anthropology and narrative studies in the latter part of the twentieth century. In autoethnographic writing the observer and observed, the narrator and narrated are further problematised by being the same person. This creates complex challenges for questions of voice and authenticity in this study. In autoethnography the relationship between observing and being observed is difficult to unravel and presents new sets of questions about objectivisation and other issues of representation (Richards, 2008). Autoethnography tends to have an interpretive aspect to it that allows it to act as a means of examining and interrogating assumptions.

Starting from the premise that each event of illness is unique (Hahn, 1995), I see each event of becoming well as unique too. Despite my academic and theoretical framework, my story of my experience of lengthy ill health and subsequent "wellness" is mine alone. My aim in writing about it is not to provide a generalisable pattern, but to attempt to understand and explain what happened to me. My story and the way in which I have constructed my narrative can show through thick description some of the complexities of the experience of CKD and post-transplant life. An account of individual experience is very important for this, because this is one way of potentially bypassing common linguistic ranges and acceptable plots that can silence difference and stifle voices (Ezzy, 1998). These affect one's identity (Denzin, 1995). I want to avoid normalisation and generalisation as much as I can. Through seeing more of the complexity of a narrative of life post-transplant, people living with organ failure and organ transplants, as well as people researching these states or treating them, may become more empowered.

I shall keep my narrative within the context of other illness narratives and the medical context in which I was treated, remembering that my story concerns the impact of becoming well for a person who has been chronically ill all her life, the reverse of the most typical pattern in illness narratives. My research, while being about how I see myself after these experiences, will also heed and explore the complex questions surrounding the extent to which an experience can remain unmediated when written about and whether an authentic voice is indeed possible. It is intended to act eventually as a form of advocacy by raising awareness of both outsiders and insiders, who often submit to narratives that are forced on them.

How I tell my story once I have had an organ transplant is a central issue in my dissertation. Flowing from this central concern are a number of sub-issues. Can my story change? How do I see myself: the well, the ill, the impaired, the disabled, or the afflicted? Do I see myself living in no man's land? Do I "zigzag between the kingdom of the well and the kingdom of the ill" as cancer patients in remission do (Kolker, 1996, p. 132) or do I occupy another territory entirely? And if I do, what is it?

Furthermore, I want to discover if my narrative is indeed a predictable narrative, falling into one of the several patterns that Frank (1995) and Brody (2003) describe. McDougall (2006) discusses how outsiders impose these patterns on narratives about ill or disabled people, but my research has shown me that insiders often impose patterns on their narratives too. It is expected that one's story will show an abstract meaning, such as "courage under adversity", "tragic waste of human potential", "heroic triumph" or "the making of a guru/saint/prophet" (Richards, 2008). Meaning(s) can be found, but in a postmodern world these may not lead to a "Grand Universal Theory". If narratives are too simple and too containing or normalising, they can prevent understanding. Illness "embodies contradiction and multiplicity" (Good & Good, 1994, p. 841).

I chose an insider approach, because illness and disability are often observed from the outside. I wanted to show what it is like living the life, feeling the feelings, rather than taking notes about it. I wanted to show what it is like living in limbo, with an invisible "disability". I did not want my voice mediated and nor did I wish to mediate the voices of others, because I wanted to avoid the "problems of appropriation that so often distort and undermine collaborations between nondisabled academics and 'their' disabled informants" (K & Duncan, 2006, p.291). I did not want to turn myself (or others) into a subject again.

I want to use my own story as a means to understand my own circumstances. I know my story as an insider, although it is the story of being an outsider. I know my story intimately. And I can tell that one paradigm alone will not do it justice. I have found in writing my story so far that I

have nonetheless turned to literature to explain some of my narratives. I have also found these literary narratives only partially satisfying because they are not my own story. They have, however, helped me to articulate aspects of my own story or at least, in trying them out, I have seen that I need to find different paradigms. Hence I have chosen autoethnography, a postmodern approach that allows me to blur, blend or braid genres and to articulate something of the doubleness of identity and multiplicity of meaning that the experience of illness and the writing of illness create.

## **1.6 Autoethnography as research design**

### *1.6.1 Why autoethnography*

Qualitative research should not be generalisable (a requirement of quantitative research); instead it requires thick description, critical analysis and reflection (Denzin & Lincoln, 1998a; Denzin & Lincoln, 2005; Goodall, 2008). Mayan (2009) describes qualitative research as “primarily naturalistic, interpretive, and inductive” and “[b]y studying naturally occurring phenomena, qualitative researchers attempt to interpret or make sense of the meaning people attach to their experiences or underlying a particular phenomenon” (p.11). In qualitative health research, researchers need to go further, because of the overwhelming amount of quantitative research alongside which they must work (Thorne, 2011).

It is especially important to remember that qualitative health research should show what quantitative research hides, or it should question assumptions and fill gaps in knowledge so that better decisions can be made for people in health care (Thorne, 2011). In a postmodern era traditional ideas of authority and genre have been problematised and no longer do the old divisions between expert and lay person, insider and outsider, academic and non-academic hold. Narratives or stories can be used in a variety of ways in postmodern research and especially in postmodern qualitative health research.

This is not, however, unproblematic. It is important that such writing adheres to standards and to achieve this, various researchers (Goodall, 2008, Richardson, 2000, among others) identify certain criteria for using stories appropriately in research. These criteria generally concern making a substantial contribution to the field, being part of academic dialogue, impact on self and/or others, and reason for telling the story. Other criteria include aesthetics and reflexivity. I return to these in my final chapter.

In a postmodern age it is difficult to accept the idea of a transcendent truth or a purely objective writer or reader. Because of this, I have chosen autoethnography as my research design and I discuss this in more detail in Chapter 3. Briefly, Lionnet defines autoethnography

as “the defining of one’s subjective ethnicity as mediated through language, history and ethnographical analysis; in short, ... a kind of ‘figural anthropology’ of the self” (1989, p. 99). Autoethnography is a type of phenomenological research that derives from an individual’s experiences. This allows me to blend personal narrative and research in different ways. Not only can I blend different genres, but I can do this in a variety of ways and each of my chapters is a different way of blending them. As an autoethnography, my research is exploratory by nature and I have treated writing as a means of knowing and discovering (Richardson & St. Pierre, 2005). It is postmodern in that the way it is written has become its epistemology.

Through the chapters of my dissertation I narrate my own experience of chronic kidney failure, dialysis, transplantation and life post-transplant. This will be carried out against a backdrop of illness narratives in general and renal-related narratives in particular to provide a context and, to some extent, a dialogue between my narrative and the others. While autoethnography is central to my research, it needs to be seen in the context of other types of illness narrative and will, indeed, talk to these narratives as it progresses, in this way showing my relationship to others in my situation, a type of meta-textual ethnography.

Initially I wanted to show what my experience of kidney disease, dialysis, transplantation and life post-transplant was like, so that people who have not had it would understand (Mayan, 2009). I discovered as I went along that I needed to understand the experience better myself. I also needed to understand myself better. And I needed to understand the experience of writing about it all too, because that experience is different from the lived experience, but very important in understanding it.

As time went on and I did more writing about the transplant and related issues, my writing revealed to me constantly that I did not always know as much about my own experience as I at first thought. I was surprised to discover, for example, that I had two stories of the experience of dialysis that had existed alongside each other for nearly 20 years without my being aware of this. Another reason that I could not tell the whole story was because I did not know all of it. I shall never know, for example, what actually caused the Haemolytic Uremic Syndrome that destroyed my kidneys. It seems HUS usually (but not always) develops from e-coli, but not in everyone who comes in contact with it. You can come in contact with e-coli through a variety of sources, none of which I encountered (as far as I know).

Some things I knew, but could not speak of them. You learn, as a person with a serious medical condition, to choose your audiences carefully (Weingarten, 2001). Other things I was not ready to discuss. Some parts of the story were other people’s stories. I so badly wanted the story to be all mine, but of course our stories are mosaiced with other people’s stories, the



stories of our culture, of our collective mythologies (Clandinin & Connolly, 2000; Frank, 1995, 2010; Good & Good, 1994; Mattingly, 1994; Nelson, 2001):

The ill body's articulation in stories is a personal task, but the stories told by the ill are also social....The shape of the telling is molded by all the rhetorical expectations that the storyteller has been internalizing ever since he first heard some relative describe an illness, or she saw her first television commercial for a non-prescription remedy, or he was instructed to 'tell the doctor what hurts' and had to figure out *what* counted as the story that the doctor wanted to hear....Whenever a new story is told, these rhetorical expectations are reinforced in some ways, changed in others, and passed on to affect others' stories. (Frank, 1995, p. 3)

As the teller of my "own" story I add to, assimilate or create a counter-story (Nelson, 2001) to others' plots. To what extent can my story be my own? Typically autoethnography concerns capturing or representing experience through writing in various ways, but I find that the act of writing itself is not examined enough. It is not an innocent act (Denzin, 1999).

### *1.6.2 How I am using autoethnography*

My work differs from other renal narratives I have found in that it is longer and more descriptive. It deals with a longer period of life, not only the time leading up to transplant and the immediate period afterwards, but a childhood and adolescence of chronic illness and 20 years of post-transplant life. It is about someone ill becoming well, while most illness narratives concern a well person becoming ill (Bauby, 1997; Broyard, 1993; Cojocar, 2007; Cook, 1996; Etherington, 1991; Ettorre, 2005; Frank, 1995; Hermans, 2006; Klug & Jackson, 2004; Kolker, 1996; Oakley, 2007, and so on). Most transplant stories end fairly soon after transplant (Cojocar, 2007; Etherington, 1991). My illness narrative does not endeavour to resolve liminality and is recursive. Self-reflection is an important part of qualitative research, because the researcher's role and influence in the research project can be substantial. The word research implies "to search again", to go back over something, to return. It finds its most fertile grounds for searching in the liminal spaces, the unexplored areas in between, and the littoral zones.

I wanted to escape the "academic voice" – that voice that takes an authoritative and omniscient stance, and that controls and organises information into a linear argument. And yet, here I am at the beginning of my dissertation, explaining how the argument will proceed and how my narratives will work.

My only consolations are that (and here I must tabulate them academically for ease of reading): a) I can draw attention to the process I underwent and not pretend that my final (and



accidental) conclusion is an immutable truth of which I was always aware; b) I have told some of it; c) the complexity and messiness of narrative are like the complexity and messiness of life; d) the story can and will always change; e) no narrative is one narrative, all are plural; and f) I can put some of my conclusion into my introduction, making my text non-linear, because in academic writing you usually write the introduction last, but pretend you knew it all along by putting it in the beginning.

I hope that my work will not unfold so much as explode. It should backtrack, jump about and cross itself out. By saying, it should unsay. It should omit and leave things unsaid. Only by so doing can it come anywhere near to capturing the contingency and messiness of life. I hope that whatever else it does, it will not remain static, but be dynamic, changing from sense to nonsense, and back, from one shape to another, because in so doing it remains alive. And when the text is alive, the reader is alert. I want my writing to argue with you and to perturb you. I do not want you to conclude about it, even though I must. I want my story to remain a thorn in your side, or at least a burr on your skin. It should chafe a little, not fit into familiar pigeonholes. Some of my stories will seem to negate others. This emerged in the telling of them and I have not changed this because the stories are all true and when taken together, the “whole” (as it exists) is true too.

Recursiveness in illness narrative is not explored enough. We want life to be linear, but it is not. So we create narratives that are linear in the hope not only of “making sense” (Bury, 1982; Frank, 1995; Kleinman, 1988), but also of moving things along. If we can obtain closure, then we can close the chapter or even the book. However, life does not always work this way and especially not in chronic illness. In the course of one’s life one might find oneself in the same or a similar spot again and again. You might need more than one transplant. I find myself periodically returning to the sick role for various reasons (and I seem to adapt to it very well).

One does not simply “get well”. If nothing else, after a serious illness there is emotional and psychological fallout to be dealt with. Forever after a life-threatening experience, you are left vulnerable. Unidentified fevers scare me to the point of making my heart pound with fear. Colleagues at work must find me melodramatic when I tell them breathlessly that I am running a temperature and am too alarmed to concentrate on my work. For them it is some or other bug. For me it could be the start of my transplanted kidney rejecting. This can happen without warning or provocation even years after an apparently successful transplant. Needles give me anxiety attacks. Not wanting to appear childish, I have learned to hide this from others. I have had to have so many. And I shall always have to keep returning to the blood room. Of that I can be sure.

## 1.7 Structure of chapters

The introduction to my dissertation has given an outline of why the insider voice is so important in writing about illness and has situated my study in this field. It has also introduced the problematic concepts of liminality, littorality and dysappearance as important parts of dealing with chronic illness in a meaningful way. I have looked briefly at literature concerning kidney disease, because it provides a context for what follows in my autoethnography of my experience of kidney disease and organ transplantation.

The literature review (Chapter 2) gives an overview of illness writing, with particular focus on writing about kidney disease. The field of illness narrative and pathography is vast so I have had to be selective. I want to achieve two things in this chapter: an understanding of how liminality, littorality and dysappearance are treated as part of the experience of chronic and acute illness, and specifically how writers about kidney failure, dialysis and transplantation address this. This will go part of the way to explaining why I have decided to write about my own experience of kidney disease, dialysis and transplantation, and why I decided to do it in such detail. My research aims to continue the insider voice tradition, but to approach the telling of the story of kidney disease, dialysis, transplantation and life post-transplant from a theorised, academic view that recognises the complexities and implications of liminality for this condition. My literature review will show why this type of research needs to be done.

In-between spaces and “third” spaces (Garber, 1997) are where autoethnography flourishes (Denzin, 2009; Jones, 2005) and this is the topic of the third chapter. Autoethnography, the methodology I use to carry out my research, is a form of insider writing that can be produced in many ways and is particularly useful when understood in a postmodern framework. I discuss this largely in terms of liminality and littorality. The rationale behind autoethnography, its advantages and limitations and its relationship to writing about illness are discussed here. My approach to autoethnography is explained within this context.

My own narrative is woven into the more theorized parts of my dissertation (introduction, literature review and methodology) in order to create a text that is autoethnographic, internally dialogical and not a study of narrative as data. Combining personal and academic genres in this way is intended to create a blurred genre that I hope is going to provide a more thorough exploration of how I tell the story of my illness experiences than would be achieved by using one or other genre alone. This is itself a third space that I hope will express the “third-ness” and changeability of my experience and the challenges of telling the story of this. This blurring continues through the dissertation to create different effects. Chapter 4 concerns CKD and ESRD, Chapter 5 dialysis, and Chapter 6 the life after transplant.

My experience of kidney disease could be seen to have taken years out of my life, but I struggle to conceptualise it this way. My illness began when I was eight months old. I finally went onto dialysis when I was twenty-one years old. Was I away from my life while ill? Where was I then? Compared with what? I didn't know any other way. Illness writing often talks about illness as a rupture from normality, which is seen to be health. Little of this type of writing is about people who have been ill from early childhood, possibly because for them (us) normality is illness. Chapter 4 considers the different types of liminality that I experienced growing up with damaged kidneys during the twenty years of increasing impairment.

Although I spent only 11 months on dialysis, the chapter on dialysis (Chapter 5) is of similar length to the one on the gradual slide into ESRD, because the structural integrity of the chapter represents the intensity of the experience. Dialysis was a life-saver. Nonetheless, I frequently had to admit while on it that it was not really a life style, but a test of endurance. It is intermittent life-support. For me it was also a type of limbo or liminal stage between life and death, but also between sickness and health, between having kidneys that didn't work and the possibility of having one that did. Dialysis was itself a curious mixture of being well and ill. I wanted the chapter to show the complexity of the experience, but also its arduousness and repetitiveness.

The section about transplantation is largely concerned with living with a transplanted organ many years down the line, because I want to show how the experience is about being "normal" and being a "patient" simultaneously, a truly littoral experience. I also wanted to demonstrate how experiences change over time. Most narratives about transplantation are medicalised in that they concern the period of having the medical procedure and what happens immediately afterwards, itself a medicalised approach to writing about the experience in that the result can be a story largely about a medical procedure (Cojocaru, 2007; Etherington, 1991).

Most qualitative research about transplantation is about the ethical issues of transplantation or the change in status of the patient as they cross over (some examples are: Baines & Jindal, 2003; Fox & Swazey, 1978; Fox & Swazey, 1992; Lock, 2002; Scheper-Hughes, 2007; Sharp, 2006; Sque, Payne & Clark, 2006). I find much of the qualitative research a somewhat medicalised representation of the transplantation experience. While it does serve a function to inform lay people and people awaiting transplant and to show the importance of the donor, donor's family and the medical team, it is a part of the experience in which the recipient is largely passive. Furthermore "having a transplant", from my perspective of being a recipient, is largely about sustaining the transplant after surgery and living with the after-effects, side-effects and issues of identity.

Liminality, littorality and dysappearance of different sorts are discussed here. I have been fortunate to have had (so far) a successful transplant. Twenty years later my kidney still functions as a normal kidney should and the side effects of my medication have been minimal. I can lead a normal life. I haven't had to deal with complications, rejections or kidney failure. I am no longer ill. And yet I take medication every day to prevent my kidney from rejecting. I must remain vigilant about my health, because it is not guaranteed and there are things I should not do. I tire easily and I still don't know what normal tiredness is. How long should I work before taking a break? How much sleep should I get at night? I have been able to find no other work about this stage of transplantation. Even today the ten-year transplant survival rate is only about 67% (McCauley, 2004; Stegall et al., 2011). Where does this leave a person who has had their transplanted organ for twice that length of time?

Finally, in the concluding chapter, I return to looking at the challenges and tensions of autoethnography as a methodology and reflect on how I have used it in my research. My research has been an attempt to give a more than superficial look at liminality, an aspect of chronic illness that has not yet received the detailed attention that it requires, and littorality, which I consider a much more useful concept in post-transplant life. I hope in this way to add to the body of knowledge about the experience of CKD and ESRD, dialysis, and transplantation, as much more can be written about these experiences. However, despite my best efforts, my study is little more than a glimpse. A lot more work can be done here and should be done not only for kidney disease, but also for other forms of chronic illness and tertiary health care.

## **1.8 How I am writing this dissertation**

In discussing what it means to tell a story, Crites (1971, p. 300) says, "But remembering is not yet knowing". Remembering what happened is only part of story-telling and autoethnography. Telling a story is initially an act of memory, but for that story to be meaningful, for it to make an impact and to be reflexive, it cannot simply be a chain of events. For this reason I do not relate the story in one part of my dissertation and then analyse it in another.

In the introduction, as with other parts of this dissertation, I attempt to show some of the textual workings behind the final version that you are reading. Sometimes this takes the form of explaining how an idea started and how it developed. Other times I might draw attention to myself in the text to remind you that I am not an omniscient narrator. Occasionally I might draw attention to how a piece of text can be read or how it can be contrasted with another piece.

The disclosure of rhetorical constructions is, in itself, an ethical act and can be an act of resistance against power structures. Instead of manipulation, disclosure is revelation and transparency. A different type of reading is necessary in a hybrid text, such as an autoethnographic writing of illness. The processes by which we as academics read and write are seldom referred to, unless the research is about writing or reading processes. These processes are certainly seldom referred to as experiences. Autoethnographic research functions as it does because of its textual nature, which I shall elaborate on in the course of this dissertation, but this nature is seldom unpacked in research, seldom explored and (in my view) seldom understood.

My intention in writing the type of narrative I have written is to try to demonstrate something of the fragmentary and recursive nature of a lengthy illness experience as well as to show the ambiguities and changeableness of that experience. For that reason autoethnographic writing seems most appropriate. My various chapters are structured in a way that attempts to mirror the experience (ESRD, dialysis, post-transplant) itself. For instance, I experienced ESRD as chaotic and in writing about it I attempted to capture some of the messiness of the experience. I wanted my writing to reflect my emotional experience not only in what I said, but how I said it. By contrast dialysis was much more structured. The chapter on dialysis has a structure which reflects this. Life post-transplant was in some ways a return to chaos, but of a different sort. By choosing three narratives to consider, I echoed the structure of my fourth chapter where I considered three narrative “artefacts”. However, the narratives of the sixth chapter are more open-ended. In postmodern thinking, “[t]he way of saying is the what of saying” (Van Maanen, 1988, p. 68).

A narrative study is as much about the stories that are not told as the stories that are told (Clandinin & Connolly, 2000; Kermode, 1981). Silences are profound, but they might not be noticed by an outside narrator or researcher. Where possible I shall alert the reader to things left out, intentionally or otherwise. I shall not explore whether these remain silences once I have called attention to them. The challenge with this as with the rest of my narrative(s) will be to create a narrative that is self-reflexive, but that does not try to turn itself into data, but instead acts as a form of inquiry.

In the course of writing my story I found I had many stories and interpretations, sometimes of single events. Telling the story or stories as narrative and interpreting the narrative could yield two quite conflicting versions of events. Rosaldo, while not explicitly writing autoethnography, explained the phenomenon like this:

An act of mourning, a personal report, *and* a critical analysis of anthropological method, [my writing] simultaneously encompasses a number of distinguishable *processes*, *no*

*one of which cancels out the others...* the paramount claim made here concerns how my own mourning and consequent reflection on Ilongot bereavement, rage, and headhunting raise methodological issues of general concern in anthropology and the human sciences. (Rosaldo, 1989, p. 11-12)

Can I claim something similar? My paramount claim concerns my own experience of a life-long chronic medical condition and consequent reflection on the nature and symbolic significance of this condition and my understanding of it. This raises methodological issues of general concern in medical anthropology and the social sciences.

One thing Rosaldo's and my stories have in common is a contemplation of perturbing in-betweenness and how it plays itself out in one's own life. Rosaldo makes the point that many ethnographic studies concern boundedness and rituals, but that mourning, for instance, takes place not only in ritual settings, but also informally. However, it is usually studied in highly structured settings where it can be observed repeatedly under the same conditions. Studies about dialysis and transplantation often occur in medical settings (Fox & Swazey, 1978, 1992; Joralemon & Fujinaga, 1996; Lock, 2002; Russ, Shim & Kaufman, 2005; Sharp, 2006), but people do not live there. Their families are not there and their inner lives are not there either. Structure imposed can be misleading (Good & Good, 1994). Or as Crites (1971, p. 310) puts it, "So long as the story retains its primary hold on the imagination, the play of immediacy and the illuminating power of abstraction remain in productive tension".

In order to provide a clearer context for the telling of my own story, I use the following chapter to examine in more detail illness narratives, as well as research that uses illness narratives. In it I address some of the intentions as well as some of the problematic issues of telling a story of illness to show some of the ways in which people approach this. My interest is in how they discuss what the events meant to them and how self-reflexive they are when doing this.

## **CHAPTER 2: THE WRITING OF ILLNESS - REMEMBRANCE, REMEMBERMENT OR SOMETHING ELSE**

### **2.1 Introduction**

Ironically, in my postmodern dissertation, this chapter is a utopian project, much as Denzin describes his chapter on the practices of interpretation in *Qualitative inquiry under fire* (2009). Like Denzin, I am attempting to bring together “multiple discourses into a unified framework” (p. 117), much against my better judgement as a postmodern researcher. Doing this feels like a type of backwards deconstruction, where I go against the textual rules I set up in Chapter 1. Nonetheless, in order to give my research context and an epistemological framework, the most efficient way of doing this is to write an argumentative chapter in a traditional way.

In this chapter I am looking at only at some general ideas about illness narratives and then specifically at illness narratives of renal disease. I shall examine these latter narratives as two categories, narratives as used by researchers and narratives as written by people who have experienced renal disease, because these are the two main categories for this type of writing. My divisions are artificial in some senses that will become apparent. What should also become apparent is that there are gaps and hiatuses in the writing about illness itself, particularly in the writing about renal disease. Liminality is not easily written about (Crowley-Matoka, 2005; Good & Good, 1994; Little et al., 1998). Littorality, it seems, is not written about at all.

I have restricted my research to written documents that are in the public domain in the form of articles, stories and books. I have not explored electronic media such as blogs or video streaming, because this is a specific type of text that has its own characteristics and functions in a specific way for specific types of audience (Spyridakis, 2000). I do not have time here to explore this or the complexity of how it relates to more traditional textual types. This is something that could usefully be explored in future research, because the format of the document will influence the structure of the narrative(s) and this could have profound consequences for illness narratives in terms of more postmodern approaches to writing them.

I begin my discussion of the literature with a section about the relationships of world and text in contemporary qualitative research. I have focused on postmodernism. My reason for this is to provide context for research on the experience of illness, where the overlap between the illness experience and the research occurs in a text and through writing. Through showing how postmodern qualitative research sometimes conceptualises world and text, I can position



illness research and illness writing in terms of a theoretical framework that allows room for messiness, ambiguity, fragmentation and even contradiction, all of which I consider essential for writing about the experience of illness. I shall also be able to show where my own research fits in.

## 2.2 The context of qualitative research in the early 21<sup>st</sup> century

### 2.2.1 *World or text or both?*

A significant amount and variety of qualitative research into the experience of illness has taken place in the late twentieth and early twenty-first centuries. This area of research is a symptom of changes that have been occurring in qualitative research for some time. In the late twentieth century postmodern concerns led to a number of changes in the contexts in which research was conducted and this resulted in paradigm shifts for researchers, where perceptions of what constituted appropriate representation, legitimation and legislation were challenged (Denzin, 2009; Denzin & Lincoln, 1998a; Denzin & Lincoln, 2005; Marcus, 1998).

All qualitative work is interpretive to some or other extent (Denzin & Lincoln, 2005). For this reason postmodernism has generated profound disquiet, because it changed the way we look at the world. This change was so rapid and so extreme that it has led some researchers to believe that all there is to postmodernism is theory and reflexivity, and that these conceptualizations of the world must be entirely text-based in the sense of existing only in documents. In the early part of the twenty-first century postmodernism has been seen by some to have been replaced by a new conceptual era that makes new demands on us as researchers (Denzin & Lincoln, 2005; Richardson & St. Pierre, 2005). One of the demands is that our research is part of the world, that “the social sciences and the humanities become sites for critical conversations about democracy, race, gender, class, nation-states, globalization, freedom and community” (Denzin & Lincoln, 2005, p. 3).

From my perspective this has always been part of postmodernism’s concerns. Deconstructing texts is a way of starting critical conversations about the issues Denzin and Lincoln mention in the quote above. It is not an end in itself. As Selden says in his book of more than twenty years ago, “Deconstruction can begin when we locate the moment when a text *transgresses the laws it appears to set up for itself*” (Selden, 1985, p. 87, italics in the original). But this is only a beginning. Moving from the text to the world is a complex process. One stage of it involves revealing through one’s research writing how one constructed one’s ideas and that the researcher is not omniscient as a way of adjusting the power relations in a research project or even in a field. The transgression that has begun in the text ripples out from there into the world:

The realities of power and authority – as well as the resistances offered by men, women, and social movements to institutions, authorities, and orthodoxies – are the



realities that make texts possible, that deliver them to their readers, that solicit the attention of critics. (Said, 1983, p. 5)

In postmodern thinking the discourse of power relations, including that of the researcher, is made explicit and decentred. For this reason postmodern research often involves allowing the voices of people on the peripheries to be heard, instead of speaking for them. Sometimes hegemonies cannot be unsettled by postmodern methods, but can ironically be re-entrenched (Buzard, 1999). However, rendering the power structures visible and problematising them might at least go part of the way to changing them.

Postmodernism is born from a time of great change (Clandinin & Connolly, 2000; Denzin & Lincoln, 2005). It is a destabilising lens of a destabilised and destabilising period. It is not about certainty and answers, but about ambiguities, questions and pluralities. Postmodernism, in effect, is not about patterns, but about differences (Clandinin & Connolly, 2000) and each difference is unique. In addition, the co-existence of different perspectives is recognised, even to the extent of acknowledging that what is not said is as significant as what is said (Clandinin & Connolly, 2000).

No longer considered to stand outside of their research, postmodern researchers are inextricably part of it, the idiosyncratic lenses through which the research is seen and the “tools of research” in various ways (O’Byrne, 2007, p. 1389). “Experience is the starting point and key term for all social science inquiry” (Clandinin & Connolly, 2000, p. xxiii). Experience changes who you are and, to an extent, to study experience is to study an individual’s experience of change (Clandinin & Connolly, 2000). “I” am not generalisable and nor are my experiences. The postmodern researcher is both researcher and researched (Hollway & Jefferson, 2000; Richardson & St. Pierre, 2005), both deconstructor and deconstructed. Postmodernism is critical of its subject matter, which includes itself and the researcher. Self and subject cannot be separated.

### *2.2.2 Postmodernism and multiplicity of meaning*

Postmodern theories work from the premise that meaning cannot be fixed, because texts are splintered, many-layered and dialogical (Jefferson, 1986; Jones, 2005; Marcus, 1998; Richardson & St. Pierre, 2005; Selden, 1985). No text can have a final or single meaning. Even the “author” of the text is not the final authority. There is a “surplus of difference” that cannot be consumed or assimilated and, as a result “any interpretive framework must remain partly unresolved” (Marcus, 1998, p. 389). Something is always lost in translation between the cultures being studied and the research product. The researcher is no longer considered the authority or the owner of a (or any) truth.

So profound is the resulting destabilisation of paradigms and theories, even of texts produced during research, that nothing can remain unquestioned any longer. What emerges can be seen as “nearly unbearable truths that would make it difficult to lend special importance or justification to any practice of ethnography” (Marcus, 1998, p. 388). For instance, postmodernism does not find an external point of view possible. There is no external or objective truth in postmodernism. Instead, all of us, including researchers, are insiders with limited, local points of view. This is the reason that much contemporary qualitative research has become interdisciplinary, even to the extent of resorting to bricolage as a strategy of piecing together information, using parts of methods that seem most suitable to the situation being researched. Bricolage is the result of carrying out research in a world of blurred genres (Kincheloe, 2001), where every idea is compiled of other ideas combined in various ways (Derrida, 1978). It requires using methods that are appropriate to a particular study, even if this means adapting them, with a thoroughness that allows new insights to be derived from the new contexts (Denzin & Lincoln, 2000; Kincheloe, 2001; Lévi-Strauss, 1966).

What emerges from postmodern thinking can be seen rather reductively as experimentation and messy texts that do no more than comment on form, or that have not yet led to any resolution of internal tensions that would allow a new type of study to be born (Marcus, 1998, p. 389). However, it can be argued that no text, including non-postmodern ones, is ever finished, ever resolved or ever free of tension – and that any text is a replication in some or other way of other texts. None can exist in a vacuum, with no reference to texts that produced it. Here is what I mean.

Just as this literature review that I have been writing speaks to the conventions of literature reviews in its form and content (and to the expectations of its readers), so does it replicate a certain type of knowledge production – traditional, linear argumentation and documentation of citations to support the argument through references to other scholarly works. It is a phenomenological work (Randolph, 2009) of a certain sort that serves specific purposes, mainly that of asserting authority. However, my literature review exists in a larger document, my dissertation, which attempts to reveal and deconstruct the tensions that exist in the type of academic research from which it stems.

Does this make my literature review part of a deconstructionist project? After all, I am transgressing the laws I set up for myself earlier (Selden, 1985). Or does it contradict or undermine the rest of my project by reverting to the very conventions I seem to be attempting to subvert (Buzard, 1999)? I could argue that if I seem to have adhered to academic conventions in this chapter, I am being ironic in true postmodern fashion (but, ironically, I am not). Perhaps I have fallen into the same trap that many others have by claiming to be using

postmodern theories, but doing so through forms that pre-date them and are not themselves postmodern (Marcus, 1998). Perhaps in order to situate my work in a certain context I have had to rely on these conventions. Possibly this is a messy area of my text whose tensions cannot be resolved. It might be a type of postmodern juxtapositioning or “blocking together incommensurables” (Lyotard in Marcus, 1998, p. 390). It might be a desperate attempt at dialogism, showing the “official” perspective against my own, although I assert my authority in my “own” text and choose what to include and exclude, what to privilege and what to ignore, as researchers often do. Or do I? Perhaps, as I am combining different methods and theories in order to escape a single paradigm, I can describe myself as a bricoleur (Kincheloe, 2001; McLaren, 2001; Spry, 2001).

I think that because my literature review exists in a certain context, my dissertation as a whole, it must relate to the rest of its textual surroundings. It cannot be hermetically sealed off from them. It affects the rest of my dissertation, just as the rest of my dissertation affects it. It is subsequently postmodern in its self-reflexivity. It is part of a text, not the text as a whole. A picture changes when you see more of it and what you see depends on how you frame it (Barthes, 1981; Foucault, 1975/1991; Muncey, 2005). Not only this, but a text at any stage of production is always a palimpsest for subsequent texts, appearing ghostlike through the words that follow it (Derrida, 1980). Even a text that is not written or not included can be a type of palimpsest in another text, its very absence a presence, as I hope to demonstrate in future chapters.

For some, text is a metaphor for experience (Ellis, 2009; Hollway & Jefferson, 2000; Marcus, 1998); for me text is an experience in itself, an opportunity to reconceptualise events and to derive new meanings from doing so. A more reflexive approach to writing can usefully problematise the idea of text as metaphor or text as verisimilitude. The (as I see it) postmodern quality of autoethnography to allow the writer reflexivity in order to gain deeper understanding of his or her story, even if this renders the story messy, is a great strength. I discuss this further in Chapter 3 and Chapter 7. Autoethnography has the potential of treating narrative in a more sophisticated way than often happens.

Marcus sees reflexivity as an ideological matter, instead of a methodological one (Marcus, 1998). I see it as both. Fieldwork and writing are no longer the distinct categories they once were; one can even go so far as to say that there is “no difference between writing and fieldwork” (Denzin & Lincoln, 2005, p. 19). Because of this and because of a postmodernist blurring of the distinctions between form and content, reflexivity must be both ideological and methodological. Methodology is ideology and ideology is methodology. You will choose a methodology that serves your ideological concerns and supports your values. An implication of

this is that methodology and ideology are the representation of the researcher's biography (Denzin & Lincoln, 2005).

### **2.3 The ways in which researchers write about illness**

For much of the twentieth century researchers of illness tended to take a medical perspective or sociological perspective instead of one that showed illness from the phenomenological perspective of individual lived experience. For instance, Parsons's (1951) role-based approach to the doctor-patient dyad was immensely influential in sociological research for twenty years. Illness was seen as deviance that was assessed and sanctioned by an expert (the doctor), while the patient was the passive recipient of care and knowledge about his or her condition (Parsons & Fox, 1952).

As qualitative research encountered crises of representation, legitimation and legislation, no longer did researchers focus only on grand narratives, but they began to see that the smaller-scale concerns of individuals and local theories were also important (Denzin & Lincoln, 2005; Rosaldo, 1989). The perspectives of research into illness changed too. These developed alongside similar concerns in disability studies. Since disabilities and illness often overlap and co-exist, I have used some of the developments in the disabilities movement to explain in Chapter 1 how perspectives have changed in illness research.

To recap briefly, recent developments in disability and illness research have made it impossible to ignore the insider experience and voice (Charon & Montello, 2002; Frank, 1995; Garro & Mattingly, 2000; K & Duncan, 2006; Kleinman, 1988; Marks, 1999; Sullivan, 1986). The insider's experience of his or her own condition is a key to shifting paradigms concerning health research and even treating people with medical conditions. As health care enables people to live longer lives with medical conditions that not long ago would have killed them, we need to rethink our paradigms about what constitutes "normality", "health" "illness" and "disablement". We need to reconceptualise the idea of in-betweenness and liminality. We need to reconsider how we represent the Other. We sometimes have to see that most of us are Other at certain points in our lives.

Nonetheless, the shift to abandoning binaries has yet to be completed and people are still sometimes misrepresented by research and the media. Couser develops the implications of this further:

Thus one fundamental connection between life writing and somatic anomaly is that to have certain conditions is to have one's life written *for* one. Cultural representation

mirrors daily life. Thus people with disabilities are also vulnerable to involuntary and prejudicial representation in diverse media. (2009, p. 17)

Disability studies has been very much postmodern in its concerns since the 1990s. As Marks (1999) notes, disability studies challenges “the reductive focus on an ‘essential’ disabled person in favour of an exploration of the ways in which people are socially constructed within the context of a range of disabling environments” (p. ix). It deconstructs paradigms and representation to reveal underlying cultural assumptions about various conditions and the people who experience them. Its slogan, “nothing about us without us” (Charlton, 2000, p. 1; Germon, 2000, p. 960), is remarkably postmodern in its claiming a voice for a previously disenfranchised minority and showing that the peripheries can be as powerful as the centre – and, indeed, that the perceived peripheries can, in fact, be the centre.

Gubrium and Holstein (1998) describe the importance of the personal story as a source of experiential data, explaining that “life comes to us in the form of stories, articulated through storytelling”, although they caution that narratives do not offer “unmediated access to experience” (p. 163). Narratives always represent something about the subject and the narrator, as well as their cultural milieu(x) (Ezzy, 1998; Sarbin & Kitsuse, 1994). This can create a tension in research between wanting to be specific and to research the experiences of an individual person or wanting to generalise from that person’s experiences and revert to the lens of illness to understand a life that could be more complex than a pathology that is part of it.

Aimee Benèt (1996, p. 768), an activist for patients’ rights, explains the dangers of generalising and of using a medical narrative only to understand a person’s experience:

We are treated as identical packages or ID numbers having textbook feelings. Concrete thinkers reason that if the symptoms or diseases are alike, then it is logical that these patients will feel, think, and respond in kind.... They are unaware or indifferent that people can see their afflictions dissimilarly, suffer and feel pain in varying ways, and yet all be true and accurate in their distinct experiences of the same affliction.... We are not always seen as individuals, and we are not taken seriously enough often enough. How can we bridge this gap and build credibility and respect? What can we do as patients to help those in the medical community hear and attend to our needs?

Much of contemporary qualitative research into illness calls upon medical practitioners to remember the human element of illness and disability (Charon & Montello, 2002; Kleinman, 1988). Using narrative in qualitative research gives an extra dimension of meaning and nuance (Garro & Mattingly, 2000). This is becoming increasingly widely recognised and,

because of this, the insider perspective of illness is so important. One way in which the insider perspective on illness can be achieved is through illness narratives.

## **2.4 What illness narratives are and why people write them**

As with any other type of narrative, illness narratives fall across a broad spectrum of intentions and serve many functions for their tellers and their audiences. The following section is intended to show what some of these forms of telling are and thereby to provide a context against which to read my autoethnographic narrative.

In the wake of the crisis of representation, trying to do away with the Other, and the persistent tensions of the insider/outsider issue, it is very difficult to tell a story that is entirely one's own. Narratives are social constructions and are chosen by the teller for various reasons and for various audiences (Weingarten, 2001). Frank (1995) explains the ripple effect:

The shape of the telling is molded by all the rhetorical expectations that the storyteller has been internalizing ever since he first heard some relative describe an illness, or she saw her first television commercial for a non-prescription remedy, or he was instructed to 'tell the doctor what hurts' and had to figure out *what* counted as the story that the doctor wanted to hear....Whenever a new story is told, these rhetorical expectations are reinforced in some ways, changed in others, and passed on to affect others' stories. (Frank, 1995, p. 3)

Illness narratives are a genre of writing that developed as a response to the "othering" that many ill people experience. These narratives are narratives written by ill people themselves about their own experiences of their conditions, often as a way of reconstituting a damaged identity (Bury, 1982; Frank, 1995). As Benèt (1996) describes the situation above, one's identity may sometimes be damaged by medical science and its narratives. Benèt maintains, as does Garro (1992), that an illness narrative can create space for the complexity of that life and the individual self's experiences that medical discourse cannot. "A self that has become what it never expected to be requires repair and telling autobiographical stories is a privileged means of repair" (Frank, 2000, p. 135). Autobiography, however, is only ever really about one person. Some illness narratives allow us to confront our vulnerabilities as a community which is often ill-equipped to say the unsayable or to say what has not yet been said.

While an individual's story can serve to inform and encourage, an examination of illness narratives shows that they are complex texts that perform a number of often conflicting functions beyond their encouraging role. The majority of illness narratives concern previously healthy people becoming ill and then recovering, staying the same, deteriorating or dying

(some examples are Bauby, 1997; Ellis, 1995; Frank, 2000; Galvin, 2005; Hornbacher, 1999; Kolker, 1996; Sparkes, 1996; Woolf, 2002). Another significant theme in illness narratives is that of a person battling with a lifelong illness or chronic disability, which would take one of the three paths mentioned above.

#### *2.4.1 Illness narrative forms*

Emplotment in illness narratives has been analysed by researchers for various reasons. Some of the better known authors include Brody (2003), Charon and Montello (2002), Frank (1995, 2002), Kleinman (1988), and Mattingly and Garro (2000). As with any other type of story, illness narratives tend to take certain shapes. Frank (1995) and Brody (2003) have explored narrative forms in their respective works. It is not my intention to do a similar study here. Instead I wanted to give a sense of how illness narratives function as texts, based on Frank and Brody's work. Their narrative types overlap and I have chosen to use the terms that Frank uses for the discussion.

There is a tendency in autobiographical illness narratives to create what Frank calls "restitution stories" (1995, p. 77-96). Frank explains that this tends to happen least in chronic illness and recent illness, and that this type of narrative occurs when people look ahead to how they think things will be, look back to how things were, or were within institutions. A reason for this might be that writers with more distance between them and the illness event see the experience differently and can afford to be more philosophical about it. Chronic illness and recent illness are still having a strong influence on everyday life.

Frank describes two other narrative types: the chaos narrative and the quest narrative. Chaos narratives are "the opposite" of restitution narratives (1995, p. 97). These stories go against everything progressive about modern medical treatment and can cause anxiety, because they are without structure, hope and, by implication, meaning. Chaos narratives are "possibly the most embodied form of story" (Frank, 1995, p. 101), but in my understanding of narrative, just putting this type of narrative into words can create a sense of order that is not there. Chaos is the "unmaking of a world" (p. 105). States of chaos are a type of liminal space. Frank recommends honouring this space, but he also explains that people can leave this space once they have some distance from the crisis that dropped them into it.

From this, my impression of chaos is that it is painful and needs to be left behind if one wants to have peace of mind. It is a state where one's identity becomes unravelled. If one can leave it behind, one would develop a different identity to be able to re-enter society. If one cannot leave it behind, it is unfortunate. Chaos is one form of liminal space. I explain my views on liminality in the following chapters. For the purposes of this present discussion, there is



something about a chaos narrative that might have elements of the postmodern about it. Possibly it is not about the unmaking of a world, but the deconstruction of one. Of course, unmaking one presupposes that there is one in the first place. In some chronic illnesses the writer has never had time to experience a world free of illness. My story is one such story. Perhaps if I had developed kidney problems later in life my story might be more chaotic. As with any other narrative, a chaos narrative is only part of (a) larger narrative(s) in the writer's life and in the broader community as a whole.

The quest narrative has three stages: departure, initiation and return (Frank, 1995, p. 119). To my eyes this makes it liminal too. A person sets out on a quest by leaving behind his or her usual world, undergoes initiation and returns to their world, changed. In my case a quest narrative could be that I start out with kidney disease, have a transplant, experience wellness, then lose the kidney and return to being ill. As it is, my story involves leaving a world I knew and moving into a new one, with no intention of ever going back. It is more an adventure story or an emigration story, neither of which seems to have the same ritualistic feel. And yet mine is liminal too. I think the crux of the quest story is that one returns home – the quest is of limited duration. What happens if you have no home to return to?

When this happens, anxiety results. Frank describes writers who die of the diseases they write about, such as Broyard, fulfilling a different type of function in this type of quest narrative, but it remains a quest to convey truth. He mentions his own alarmed reaction to blood tests that “require further investigation” (p. 136), a feeling with which I am familiar, even 20 years after transplant. I think this reveals that some of us can never really go home. We never really live there anymore. We might visit it, but really we are living in another place entirely.

#### *2.4.2 Remembering or remembering*

Postmodernity, according to Frank, attempts to deal with chaos through a close examination of the particular (1995, p. 137). In addition to this, I find postmodernity a response to and recognition of the fragmented nature of life. It is more difficult than ever to sustain narratives in an age of such rapid change and in societies that are becoming increasingly complex and multicultural. We may not be able to capture such an experience, but we can allow our texts to reflect the fragmentary nature of life. A belief that narrative replicates life through verisimilitude may have its roots in quantitative research. Narrative does not replicate life. It cannot. It would take too long. It can, however, represent aspects of life performatively.

Thomas-MacLean's (2004) study of breast cancer patients' narratives, using Frank's narrative types, caused her to wonder whether the post-mastectomy narrative may be less a matter of restitution than reconstruction, since no true return to a preoperative state is possible (p.



1655). Reconstruction has an echo in surgical reconstructive practices, so the term may be especially apt for her field. I would choose the term “rememberment”, drawing on the concept of narrative repairing a damaged life (Bury, 1982; Frank, 2000). This would be what Mattingly (1994) calls therapeutic emplotment. Reconstruction has connotations of being able to reproduce events, while rememberment has more of a focus on the process of reassembling parts. The end product may not be what the original events were.

One of the first times that a shattered life is put together after chaos is depicted in the Egyptian myth of Osiris being put back together by his wife, Isis, after being murdered and dismembered by Seth, the god of chaos. Osiris returns to be king, but he is now King of the Dead and lives in that world. He can no longer live in the world of the living. When he is pieced back together, he is changed irrevocably. You can never go home after being torn apart by chaos. Rememberment differs from remembrance because it implies making something new from bits of something old; not bringing back something that was lost.

Despite this and despite the experiences that people writing about illness have had, illness narratives seldom address the rememberment aspect of writing. In many respects we live in a postmodern age, but popular writing does not (yet) truly reflect this. It often harks back to a premodern period and hence we should not be surprised that the protagonists in such stories are romantic heroes. In addition to this, illness narratives tend to serve specific functions, often one or other type of therapeutic emplotment (Mattingly, 1994). If narrative does indeed help one to heal a damaged life, it may be easier to write a story that reflects this aspiration, instead of one that performs one’s anxieties and tensions. In conversations with people when I have encouraged them to write their stories of chronic illness I almost always encounter resistance. When I ask why, my interlocutors explain that living through it was too painful and they are afraid of what they will see if they write the story. They do not hold out hope of narrative repair and they fear seeing through narrative how they really are now.

Possibly for these reasons there are not many studies of the sort I am writing: what it is like to be ill for most of one’s life and then to become well and discover how this impacts on one’s identity. A possible reason for this is that “health” is seen as the norm, even in illness narratives which purport to challenge such norms. Another reason could be that such a narrative would not conform to the prevalent notion of a “comic plot”, nor would it align itself with the just world hypothesis (Lerner & Miller, 1978), where sin is punished and good rewarded. Couser (1997, p. 294) describes generic illness narrative as “so invested in recovery that the achievement of closure often takes precedence over consideration of what dysfunction feels like and how it alters self-perception”. Although the experience of being ill all

one's life and then becoming well has been under-explored, it causes a profound change in identity and the new identity / identities that one forms are far from unproblematic.

The number of illness narratives is growing, possibly partly because these days medical science can postpone death for a number of serious illnesses. Recipients of organ transplants share some characteristics with members of this society, in that, as a result of medical intervention, they have survived an illness that would previously have killed them.

## **2.5 How researchers and people who have experienced renal disease write about it**

In this section I discuss some of the renal research and renal narratives that I find problematic or noteworthy. I am by no means implying that this is all there is to writing about kidney disease. Much of what is written is helpful and insightful, and comes at the cost of difficult, often painful experiences on the part of both renal patients and researchers (later in this chapter I discuss why Fox and Swazey (1992) left the field). I have found some of this material useful in conceptualising my own narrative. A particular piece of research comes to mind here, that of Crowley-Matoka (2005) whose recognition of what she calls "persistent liminality" helped me to see that such in-between states can indeed be written about. Eventually I was to conceptualise such in-betweenness differently from the way she did, by redefining the space as a separate (and legitimate) state of being. However, seeing that the people she interviewed about life post-transplant shared my sense of not belonging in the world of the well or of the ill facilitated the development of my own ideas.

Reading Martin-Macdonald's (2003/4) compassionate insights into the uncertainties of living on dialysis was also an occasion for self-recognition. I return to these in Chapter 5. Baines and Jindal's (2003) collection of research articles on the lived experience of kidney disease and kidney transplantation offered some validation for some of the difficulties I experienced post-transplant, despite my initial misgivings at the neo-Darwinian slant of their title, *Survival of the fittest*, which I feared was the harbinger of a book about why only the strong should be allowed to live. My fears turned out to be unfounded. Instead the book examined why life after transplant is fraught with complication and difficulties, some of which are not renal-related, but socio-economic. It made a strong case for better after-care and social and psychological support for transplantees.

Most of the research on kidney failure is written by health care professionals for health care professionals and about patients (Richards, 2008). Most is necessarily quantitative. Often researchers pursue an on-going argument about what type of donation is best, or how potential donors could be approached (examples of this include Hippen & Taylor, 2007;

Landolt et al., 2003). Substantially fewer attempt to address the psychosocial or ethical issues (Richards, 2008). Just as medical discourse, for example, tends to separate the individual body from social context (Easthope, 1994), some qualitative research seems to disengage the individual's body from its lived experience. The individual's transplanted body or dialysing body becomes a symbol or metaphor for a larger social issue and, in so doing, ceases being itself.

Scheper-Hughes (2007), for instance, has problematised the notion of organ donation by drawing attention to unethical donation practices (such as organ trafficking) and by using emotive terms ("tyranny of the gift" p. 507, "family bondage" p. 507, "sacrificial violence" p. 509) to express the disquiet that organ donation often evokes. She cites extreme examples to illustrate her point that living donation is ethically challenging. While I think her focus on the rights of the donors is laudatory, I find her apparent disregard for the humanity of the recipients disquieting. The only times they feature is to illustrate selfishness and ingratitude. She seems unaware of the trauma and distress people undergo while waiting for a transplant, the pain and suffering of having one (Sque et al., 2006) and the moral dilemmas (Baines & Jindal, 2003) they have to face. Individual lives are not important in her work, only the big idea of ethical issues in organ donation.

When I read her 2007 article I felt as if I, as an organ transplant recipient, had been rendered invisible. I had disappeared, re-emerging monstrosously (Leder, 1990; Shildrick, 2002) as an example of a greedy and ungrateful consumer revelling in the benefits of organ transplantation. I experienced it as a form of Othering. Whenever I read this sort of document, I am painfully aware of two things:

- 1) I cannot avoid reading it as an organ transplant recipient; and
- 2) I have to see that people like me are not the intended readers. We are the ones written about. We are the subjects. We are "them".

As a result my reading is transgressive and when I annotate the articles I feel as if I am writing graffiti. The readers are able-bodied people who have appropriate (or appropriated) academic distance from the subject. They are not involved.

Often this type of analysis will be about organ transplantation in general, with a subsection on kidney transplants and will often be gloomy and strangely unpeopled manifestoes on the state of the world, using people's lives to illustrate ideas (Richards, 2008): *Kidney for sale by owner: Human organs, transplantation, and the market* (Cherry, 2005), *The courage to fail: A social view of organ transplants and dialysis* (Fox & Swazey, 1978), *Spare parts: Organ*

*replacement in American society* (Fox & Swazey, 1992), and *Twice dead: Organ transplants and the reinvention of death* (Lock, 2002).

Organ transplantation occupies a unique niche in illness and recovery. Organ recipients live because other people's vital organs sustain them. Much debate has raged around the ethics of this type of intervention, particularly concerning the ethics of how the donated organ is obtained. Organ recipients' stories are expected to show gratitude with an element of surprise, which could be a way of challenging any notion that they were hoping to profit from another's death. The transplanted organ is constructed as a "donation" or "gift", which gives it the quality of being freely given. Scheper-Hughes (2007) problematises this notion. Sque et al. (2006) completely reframe this gift as a blood sacrifice. Where does this leave the recipient?

There is a wealth of literature about organ donation from researchers as varied as Joralemon and Fujinaga (1996), Lock (2002), Scheper-Hughes (2007), Sharp (2006), and Sque et al. (2006). However, examining this literature in full falls outside the domain of this dissertation. I shall further restrict my discussion to literature about kidney failure and kidney transplants only. As with other illness narratives and illness research, ESRD, dialysis and transplantation have been emplotted in certain ways in biography and in academic writing.

### *2.5.1 The use of renal narrative in research*

Literature about renal disease tends to cover transplantation (the preferred therapy: McDonald & Russ, 2002; Wolf et al., 1999) and dialysis (the last resort that many people with ESRD end up on, even if they have had a transplant). For this reason I have discussed transplantation first. Dialysis is a gruelling experience. Dialysis patients are often exhausted and depressed, which can make them less forthcoming in interviews than excited patients who have been given a second chance at life (Fox & Swazey, 1992; Martin-McDonald, 2003/4). ESRD itself receives relatively little attention, as does long-term life after transplant. I discuss these areas elsewhere in my dissertation (Chapter 4 & Chapter 6).

#### *2.5.1.1 Transplantation*

As discussed earlier, most writing about organ transplantation is from the medical (or medicalised) perspective. Some writing is by people who have undergone transplants themselves. These narratives tend to have "comic plots" that end with them on the brink of, or enjoying, a second chance at life (Etherington, 1991; Klug & Jackson, 2004). These "comic plot" narratives tend to read like 'how to have a happy transplant' guides that justify suffering and "explain" a second chance at life. They are not very different from the medical narratives in that they tend to have a generalising, linear approach to organ transplantation, are often focused on medical events and outcomes, thereby rendering simple the philosophical and

ethical issues, because these are not their focus. A number of key questions remain unasked in these narratives and a number of perturbations remain below the surface. This dissertation aims to address some of them.

One of the perturbations I shall not be addressing is the very idea of transplantation itself. Either the kidney comes from a cadaver donor (as in my case) or from a living donor who is usually related to the recipient. In either event others (the donor, the donor's family who must decide to donate the donor's organs) undergo pain and suffering so that the recipient may live. This can cause recipients much guilt and ambivalence.

In addition to this, transplantation is difficult to categorise. It is not like anything else. It is a therapy (but not a cure) for a fatal disease. It concerns combining the parts of one person with another. This is why it has been seen to "threaten the boundaries of self and life" (Couser, 1997, p. 13; Faber, De Castell & Bryson, 2003; Helman, 2007). Fox and Swazey (1978) describe the importance of organ transplantation as lying "as much in [its] social and cultural significance as in [its] medical and surgical value" and it is to be associated with "key structural attributes of modern medical research and practice and with the values and beliefs on which these attributes are based" (p. 376):

[T]ransplantation ha[s] been extensively practiced and brought to public notice at a historical juncture when there are indications the kind of modern society in which [it has] been developed is moving into a new evolutionary phase. Some of the metamedical phenomena and issues connected with ... transplantation are integrally related to societal patterns and to alterations they are at present undergoing.

Organ donation can be considered the ultimate gift (Fox & Swazey, 1992). The nature and implications of this gift are often discussed in qualitative research on organ donation, drawing on Mauss's (1969) assertion that certain gifts are given in a way that is "in theory voluntary, disinterested and spontaneous, but [is] in fact obligatory and interested" (p. 1). In renal transplantation, organ recipients can receive organs from live donors. This creates a number of unique situations for both donor and recipient. Potential commodification (Scheper-Hughes, 2007) of body parts is of great concern to people, because it raises issues around the nature and value of human life and death, the boundaries of the self and what Helman (2007) refers to as "cultural definitions of anatomy and physiology" (p. 44).

With the exception of the research of Sque et al. (2006) and Scheper-Hughes (2007), transplantation tends to be described in the literature I have cited in this section as "a second chance at life", although this contentious topic is viewed differently in different parts of the world (Helman, 2007). The insider experience of undergoing a transplant and adjusting to the

new organ is often discussed in contrast to a medical view that transplantation is just another form of dialysis. Fox and Swazey (1978), for instance, take this view in their discussion of the social significance of these processes and usually discuss them together. For the recipient of a kidney transplant or the patient on dialysis, however, the experience of these processes is worlds apart.

Even so, transplantation tends to be seen in terms of the actual operation and its aftermath, although the object of transplantation is to give a person a new lease on life. In other words, transplantation is still seen primarily from the doctors' perspective, as a medical procedure that they perform. For a person who has overcome a dread disease, a transplant is just the beginning of a whole new type of life. This life is seldom explored very far, because on average, transplants do not last very long. Even nowadays a third of all transplanted kidneys fail, die or reject before the tenth year (McCauley, 2004). I have not found any articles on the experience of transplantation after the tenth year and there is very little written about it by people who have had transplants. I have found nothing in book form.

#### 2.5.1.2 Dialysis

Beyond transplantation, Fox and Swazey's (1978) sociological interpretation of dialysis is a key text in non-medical renal research. The phenomenon of waiting for a kidney is an "activity" that takes up much of the time of someone on dialysis. Waiting can become a way of life. This needs to be further examined, because researchers tend to treat dialysis as a temporary measure, a type of liminal space through which one passes en route to health. For many dialysis patients this is not so. It is how they will live until they die. Sometimes they live very well, sometimes very badly indeed. Embodied experience is a crucial concept when discussing dialysis, but there is relatively little written on it, because most of the writing on dialysis is by medical professionals who have never been on it themselves.

Research done by nursing practitioners tends to be the closest to trying to capture the lived experience and identity issues of dialysis patients (examples include Caress, Luker & Owens, 2001; Martin-McDonald, 2003/4; Scott, 1999; Thomas-Hawkins, 1999; White & Grenyer, 1999). Dialysis is a topic researched by nursing practitioners and nursing researchers, because dialysis nursing is a specialised area of nursing care. Nurses are not only responsible for the medical and sometimes technological aspects of dialysis, but also for sustaining workable and beneficial relationships with patients who are often long-term and who need various types of psychological and relational support. Because of this, nursing research into dialysis tends to be the result of long periods of working with such patients and observing their needs; it is also compassionate and insightful, with a realistic appreciation of what dialysis is

like. Their approach to research tends to be iterative and to their patients tends to be dialogical, showing an acceptance of different ways of knowing and understanding.

In the literature beyond nursing, there are some surprising interpretations of what dialysis means: “People with renal failure epitomize Haraway’s (1991) notion of a ‘cyborg,’ in that they are both organism and machine” (Faber et al., 2003, p. 144). Haraway’s (1991) cyborg is much more than a person languishing on life support and her writing was not meant to be a manifestation of technophobia. Her idea of human and machine was more focused on the inevitable blurring between people and what we make. We are all cyborgs because the distinctions between who we are and how we construct our identities are blurred too. Helman (2007) explains this in terms of symbolic skin. When we use technology often (our laptops, our mobile phones, our motor cars), it becomes part of our identity and our way of interacting with the world. It can even become a type of life-line (as, ironically, one of Faber et al. interviewees described dialysis). Haemodialysis is essentially intermittent life support, not a permanent part of one, as a pace-maker or an electronic prosthesis is. It can indeed change one’s identity and one may very well feel dehumanised and governed by technology, but the alternative to dialysis is death. Faber et al.’s article does not consider this, nor does it address the instances of people finding dialysis works well for them.

I find many other points Faber et al. (2003) make are valid, but they do not fully appreciate (and how can they?) what renal failure is *like*. At one level, there is nothing exceptionable in the claim by the authors that people on a renal diet want to eat “normal” food because they want to be normal. What the authors do not tell us is how they came to this conclusion. Did they obtain this information from the people they interviewed or did they “infer” it? If the people said they wanted to be normal, do the authors know what this means for the patients? Did the patients mean that they felt left out of normal things? That they missed the taste of some foods? That they felt jaded, bored and frustrated by a renal diet? Something else? A combination of the above? Did the authors infer from other information that the patients wanted to be normal?

These distinctions may mean little to those who look into the world of renal failure from the outside, but they may mean a great deal to insiders. A renal diet has to be experienced to be believed. It is unpalatable, restrictive and depressing. It can be difficult to adhere to because restaurants and fast food outlets don’t cater for renal diets. Faber et al. (2003) don’t discuss what the diet involves, interestingly enough, and I picked up no indication that they had any insights into it. It is precisely through an understanding of the seeming banalities and unimportant details of unpleasant diets that we may understand more about the world of the person in renal failure. Outsiders may foreground the fact of having a life-threatening illness as



key to understanding renal failure, but along with any terrors concerning mortality and illness is the experience of blandness and boredom, an experience which seems to be overlooked in outsider accounts.

### 2.5.2 “Independent” renal narratives

I have called the narratives in this section “independent” because they are not part of a research project, not because they really exist separately from other narrative forms. They are very much like other illness narratives in that they take typical forms and seem to exist for typical reasons as discussed in earlier sections of this chapter.

Most published illness narratives tend to concern illnesses that contain other sorts of cultural significance: tuberculosis in the nineteenth century, polio after the second World War and AIDS in the current era (Couser, 1997; Sontag, 1978) or organs that are “symbolically charged”, particularly the heart (Couser, 1997, p. 12). Some illnesses do not seem to get much exposure by comparison. Kidney failure is widespread and is always fatal unless treated and yet there are few narratives written about it.

These narratives usually take the form of an illness damaging an identity and being exorcised by a miraculous gift (Richards, 2008). The titles, which I alluded to in a previous article, speak for themselves: *Transplant: A new life after kidney failure – a dramatic personal account* (Etherington, 1991), *Perfect match: A kidney transplant reveals the ultimate second chance* (Hermans, 2006). There is a quantity of self-help books on the topic: *Your critically ill child: Life and death choices parents must face* (Johnson, 2007), *Coping with an organ transplant: A practical guide* (Parr & Mize, 2001), *Kidney dialysis and transplants* (Stein & Wild, 2002), and brief anecdotes in some of the *Chicken soup for the soul* books (Canfield & Hansen, 2003; Canfield, Hansen & Reber, 2006). Most of these are written by care providers, friends and family.

Lori Hartwell (to whom I return in Chapter 6) combines both personal narrative with motivational and self-help ideas, “to instill ‘health, happiness, and hope’ into the lives of fellow patients” (Hartwell, n. d). What makes her work different from some of those above is that it is more complex and written from an insider point of view. While focusing strongly on optimism and humour, Hartwell is all too keenly aware of the burden of chronic illness. Even so, her book fits very much into the motivational speaker mould, coming across sometimes as prescriptive and sometimes at the cost of simplifying some of her concerns. Very few of the abovementioned works go beyond the crises caused by organ failure and drastic medical treatment (Richards, 2008).



### 2.5.2.1 Two renal narratives that seem different, but are much alike

In a previous article I discuss two renal narratives in detail (Richards, 2010). Through discussing the use of title and themes, I show that although they seem so different, one narrative being the narrative of a Hollywood fashion guru (Cojocaru, 2007) and the other the narrative of a very conservative religious family (Hermans, 2006), they are essentially telling the same story. They both adopt a narrative form not discussed by Brody (2003) or Frank (1995), the redemptive narrative.

For different reasons both narrators describe the experience of traumatic loss of a vital organ as eventually revealing a hidden gain that allows the patient and his family to experience redemption from vaguely conceived sins. In other words, a benefit is seen to come from this suffering and the Just World hypothesis (Lerner & Miller, 1978) is allowed to persist unchallenged. The price paid is that the tensions and uncertainties in the narratives are never truly addressed or resolved so much as silenced. These tensions and uncertainties are what would make these texts (in Marcus's terms, 1998) "messy" and inconclusive. The narrators cannot bear to confront them, possibly because they may fear an unspeakable truth that may flow from the realisation that sometimes traumatic losses simply happen and one's life changes forever. Both narrators wrestle with the idea of liminality, especially persistent liminality (Crowley-Matoka, 2005) or sustained liminality (Little et al., 1998).

In addition, both narratives make a strong connection between illness and pollution. Douglas (1966) argues compellingly that rituals of purity and impurity make sense of experience and allow people to atone for real or perceived pollution. In a conference paper (Richards, 2009a) I explained that narrative can play the role of such a ritual in contemporary society if it clearly delineates an "impure" experience, such as one that threatens what we need to believe (for example, that we can control our destiny) and brings an end to liminality. Perhaps after performing such a ritual one may be readmitted into society and leave one's liminal condition behind. I saw the two narratives as such narratives. However, since then my views have changed on the usefulness of liminality as a way of describing in-betweenness in chronic illness. As I discussed in Chapter 1, a more useful term for this in-between state could be littorality.

In the two narratives I discussed the theme of redemption shows the life after the event as an improvement. Illness and a changed body image have led to spiritual insight. Loss has been justified. This provides narrative closure, because describing life after suffering as better is one way of making that suffering meaningful. This is not necessarily a bad thing, but it does rob the experience of complexity. A danger I see in a story that suggests life is somehow better or more profound after a catastrophic event is that it positions the narrator as a type of guru who

has unique access to the truth and makes the story a type of moral tale. To some extent, both Hermans and Cojocarú do this. For them illness and a changed body image are the price for insight, wisdom or spiritual growth that others seem to obtain without such devastation, although this is never discussed. Instead loss is rewarded and explained through narrative. This has profound metaphorical and moral weight, cultural resonance and provides the longed-for (and socially acceptable) narrative closure.

This is an instance of how shared and acceptable narrative plots may lead to “sins of omission” and serve to silence and oppress (Ezzy, 1998). Such plots also affect the identity of the narrator, because they provide only a few acceptable roles for the narrator to play (Denzin, 1995). For a narrative to be “so invested in recovery” that closure may become more important than “consideration of what dysfunction feels like and how it alters self-perception” (Couser, 1997, p. 294) has profound consequences for illness narratives. Redemption through meaningful suffering can become more important than what happened when one was ill, or the nuances of whom one becomes afterwards. What often slips through the narrative cracks is a consideration of a persistently littoral identity.

A new life requires a new identity, but by the end of both books the transplantees still vacillate between being ill and well, and between who they once were and who they hope to become. Cojocarú (2007) seems to recognize an underlying perturbation here and, by the end of his book, teeters on the brink of accepting that his life can never return to what it was. His life is messy and flawed and he sees that he needs to accept this. Poignancy infuses his final pages. He does not like this realization and will have to work hard to accept it. He has lost so much through his illness that even trying to see this as a gain (wisdom and insight into the true value of life) rings a little hollow.

#### 2.5.2.2 An anthology of renal narratives that serve various functions

Hutchinson and McCallum’s (2000) collection of 100 patients’ stories shows more of the complexity of the experience, although the pieces are very short. Hutchinson is a medical doctor in their renal unit and he may have treated some of the writers. If the pieces were commissioned, the writers may have been asked to write on specific topics or to specific themes. Nonetheless, being able to read many fragments of people’s own interpretations of their experience and to see them side by side may allow one to see a more composite picture of the multiplicity of experience and the complexity of the situation.

Their anthology is entitled *Heroes*. Denzin (2009) describes the pervasiveness of the romantic hero even in our (post-)postmodern age. Just as the researcher can set himself or herself up as the hero who can tackle and give meaning to the research subject’s life situation, the

narrator of his or her own story can reproduce “sad, celebratory and melodramatic conceptions of self, agency, gender, desire, and sexuality” (p. 125), casting himself or herself as the hero of a narrative that allows meaning to be produced in socially acceptable formats, such as being the agent of one’s destiny or looking on the bright side of life and making something good out of a tragedy. Older forms of heroism would involve having a fatal flaw and being destroyed by it.

The narrators in the anthology do not, however, come across as conventional heroes, full of pluck and derring-do or tragic grandeur. They did not set out to be heroic and for the most part do not assume a heroic stance when writing. Their stories show a wide range of experiences and the effect of this disease on many different lifestyles. The editors’ choosing “heroes” for the title shows that their interpretation is somewhat different from what is generally understood as a romantic hero and in email correspondence with me they acknowledge that the idea of a “hero” is complex (T. Hutchinson, personal communication, 31 December, 2009). The object of the book was to help patients, partly by allowing them to tell their stories and be heard and recognised by being called heroes, partly to allow other patients to benefit by reading about their experiences (Hutchinson & McCallum, 2000). This can allow people to identify with others’ experiences and come to terms with their own. As Moses Baker, one of the contributors to the anthology, puts it: “If the information about myself and how I coped with my kidney failure helps other people, then maybe I’ll see myself as a hero” (p. 37).

I found myself identifying with several of the stories in the collection, particularly that of Kristine Shapiro (Hutchinson & McCallum, 2000), an academic who is roughly my age and underwent her therapies at roughly the same time. She describes a sensation familiar to me of how time seemed to come to a stop and how she spent her adolescence in a “zombie-like trance” (p. 167). The difference is that Kristine’s transplant did not work and mine did. Even today, all these years later, with a kidney that has remained uniformly normal for nearly two decades, reading a story like that makes me feel sick to my stomach. It gives me a type of psychic vertigo, which I discuss further in Chapter 6. For Kristine dialysis is a liminal space between transplants: “Despite the daily routine of dialysis, I can see beyond this vale to a future filled with purpose and meaning, laughter and joy” (p. 171). Her narrative ends at that point. If she does not get a transplant, this “vale” will be her life. She cannot afford to think about that. I shall return to this in Chapter 5.

The weird in-betweenness of post-transplant life is often discussed in the anthology, as Laureen Bureau-Gould explains: “It took 10 years for me to realise that first of all I’m still sick” (Hutchinson & McCallum, 2000, p. 29). A tension exists between the “happily ever after” narrative (p. 107) and this one. I discuss this further in Chapter 6. Briefly, I can fully

understand why one would want the story to end happily, after so much suffering and dread. Also, one has to fight so hard for so long just to survive. It is mentally exhausting. After fighting so hard to keep going for (often) a long time, one develops the habit of fighting, looking on the positive side, being cheerful. It is self-defence. When one is so vulnerable, one cannot afford to make oneself more vulnerable.

Nonetheless, many of the narratives still fall into recognisable patterns. Poignantly, a number of the stories are intended to fit into the pattern of “I was well, I fell ill, I had a transplant, and then I got well again” mould, even when the narrator does not recover. Illness is often constructed as a temporary space between two permanent ones. Another variant is “I lost my health, but gained so much more”. It is this variant to which Cojocar (2007) aspires in his book-length narrative. Martha Zanna’s story (Hutchinson & McCallum, 2000, pp. 96-98) and that of Maurice Kouri (p. 75) show this. They both have a redemptive quality that, from my experience, can only ever be part of their story.

Some of the narrators felt that they had done something to deserve suffering as they had: “when I was a kid I felt that God was punishing me ... because I was sick I was bad and was being punished” (Hutchinson & McCallum, 2000, p. 25, punctuation as in the original). Illness is often associated with pollution (Douglas, 1966; Richards, 2010). In kidney failure this is not surprising. Kidneys remove toxins from the blood and so it is easy to think of one’s blood or even oneself as dirty. This was a theme that I found in the narratives by Cojocar (2007) and Hermans (2006) too.

Some of the writers in Hutchinson and McCallum’s anthology see only the bleakness and loss and their narratives are tragic (Anonymous, aged 67, p. 32-33; Siméon Likhonay, p. 22; Georges Zeitoni, p. 83). Others know they can never go back to what they were before (Dimitra Boufonos, p. 18) and some remain ambivalent about their circumstances (Anonymous, aged 40, p. 104). A constant question is: Who am I now? Seeing that the miraculous surgery has not truly made you well or has even failed is very disturbing. Passing and concealment (Goffman, 1963/1990) can become a way of life, if you want to keep your job. Antonio Batista (Hutchinson & McCallum, p. 74) has learned that, although he is healthy enough and can work, if he tells people he is on dialysis they won’t employ him.

People like us have no name, other than being “dialysis patients” or “transplantees”. We are not strictly speaking in remission and hence we cannot really be part of remission society. We are not healed. We need a narrative or narratives of our own that better explain our circumstances.

### *2.5.3 Writing the ill renal self through blending genres and roles*

A different type of text is created when researchers and renal patients collaborate. This is not unproblematic, however. Ideally such research writing should produce a new type of genre or at least a blurred or blended genre of the sort I discuss in Chapter 3. This sort of writing is designed to foreground people's lived experience, while bolstering this experience against a theoretical framework and a research methodology. In this way ideally such research can reach a wide audience of people experiencing an illness as well as people studying it in various ways. Non-renal examples include K and Duncan (2006) and McDougall et al. (2006).

Sometimes these blended-genre texts are the product of a group of researchers working with a group of patients. One of the articles I read was written by a renal patient, along with a team of researchers (Schipper et al., 2010). All researchers, Schipper (the renal patient) included, were psycho-sociological researchers. I was struck not only by the unusual combination of roles, but also by the situating of Schipper as first author. This is the only time I have seen this combination.

The article is all about her experiences. Her co-authors invited her to write the article with them. Does this mean she has more of a voice? This is debateable, since the project was not initially hers and she was chosen for the position of co-researcher. Schipper is first author, but she remains the "patient" or subject of research under others' gazes, as she has polycystic kidney disease. Privately I was saddened to realise that because Schipper is in the relatively early stages of ESRD, her experiences and perceptions of her condition are likely to change radically as her condition deteriorates. She does not yet know how difficult and frightening it will become. Cynically I can't help wondering if she was chosen not only for her experiences and background in psychology, but also because she was relatively well at the time of writing the article. From experience I can tell you that a more debilitated writer would not be able to meet the demands of research.

Allen and Hutchinson (2009) examine the role of patients and their experiences in research and conclude that this is a murky area, where the power balance is in constant danger of reverting to old situations, with the doctor or researcher choosing what will be studied, as well as what will be included, excluded, adapted and how. They go as far as saying that the power is always in the hands of the researcher or doctor. Allen and Hutchinson's concern is with Participatory Action Research, but it can be extended to any research that uses patients' experiences and narratives. Clearly this is an area that is far from unproblematic and there is a need for more research into blurred genres of this sort.

In the renal research I have discussed above, a blurring and blending of genres and roles does occur to some extent, because patients are allowed some voice in the texts. The researchers have generally worked hard to preserve the individual voices of their subjects and a certain element of dialogism is present. For instance, in articles where chunks of quotes are given, they are not entirely interpreted by the researcher for the reader, so the researcher may infer one thing from them, but they still leave space for the patient-participant's meaning to be seen by a reader. Some visibility is better than none.

Often, it would seem, the writing of academics and the writing of people living with illness may have enjoyed different ontologies, but they share the same epistemology. By this I mean that writers about illness come to writing about it for different reasons. Often that reason is personal, but it is not always one's own lived experience of enduring a disease. The underlying theoretical framework, even in the work of non-academics who are telling their own stories, seems to be a way of putting a shattered life back together and regaining some sense of normality, or at least finding a reason that is good enough to account for their suffering. For a person who has experienced kidney disease, however, this may be only a partial way of addressing issues of identity and narrative.

## **2.6 What I find problematic in these sorts of writing**

Medical and even sociological authors seldom investigate life after the transplant, when the medical crises are over. This is partly because many of them are not concerned with people as people, but rather with them as what they represent, or with medical processes and what they involve (Billig, 2011; Richards, 2008). Psychosocial writers straddle the concerns of medical writers and lay writers, tending to generalise their findings, even when avowedly performing qualitative research.

Moreover, these researchers remain outsiders because they have not experienced kidney disease first-hand. When I read their work I become acutely aware of my own appropriation of the insider perspective and of the power that gives me because I have access to information that they cannot have. When I discuss their research in my dissertation, I do it through the insider "lens". I have had to remain aware of the amount of anger I sometimes feel towards some of these writers, as I shall explain below.

### *2.6.1 Persistence of the Other*

Despite the attention paid to the Other in qualitative research, a troubling tendency remains that narrators try to conceal themselves in their writing through distancing themselves from their subjects: "they recognise no hyphen" (Fine, 1998, p. 138). Some renal examples include

Faber et al. (2003), Russ et al. (2005), Scheper-Hughes (2007), and Sque et al. (2006). They do not recognise being part of the picture they are studying. They construct themselves as neutral, as representing a “God’s eye view” or “the view from nowhere” (Hollway & Jefferson, 2000). But, as Rosaldo puts it, “there are no innocent ethnographers” (1989, p. 41). You are always involved.

Most significantly for illness research, othering constructs a vulnerable and suffering other who fits the category “pitiable, victimized and damaged” (Fine, 1998, p. 139). It essentialises and polarises categories to aid with generalising about culture (Fine, 1998). It uses philosophical discourse to understand its subjects. The result is (crudely): people on dialysis are ill and disabled (and not like us). This is my primary issue with Faber et al. (2003), Fox and Swazey (1978, 1992), and Russ et al. (2005). People on dialysis are not necessarily (only) victims or objects of pity. Nor do they completely lack agency.

As an insider I felt particular perturbation about Fox and Swazey (1978, 1992), despite their years of meticulous research into the experiences of people in ESRD and their seminal research about dialysis and transplantation. I am aware that they offer several other reasons for leaving the field, including medicine’s frequent refusal to accept limits and a willingness to view the human being as a collection of biological parts. This can lead to collusion with unethical organ procurement. Fox and Swazey’s concerns were with policies that allowed elderly and very ill people to have their deaths postponed, rather than with lived experience or with human lives that are affected by policy decisions. A large part of my insider disquiet, however, came from learning why they left the field after so many years of research. Ultimately, the vulnerability that Fox and Swazey saw rendered them vulnerable too. The last chapter of their last book, *Spare parts*, explains that, amongst other reasons, the individuals they met made them feel “sadder and more anxious” and caused them to question why people suffered so (Fox & Swazey, 1992, p. 201). At a certain level I am furious that they could leave and I cannot.

I do not see many references in their work to what the patients wanted or needed, and the book ends with the record of their own distress as researchers. Their external and subjective view was ethnographic, involving participant observation, interviewing and analysis. They also use quantitative data to assess outcomes and costs. They claim to have “watched from the inside” as these tragedies unfolded (1992, p. 197), but they could not, by virtue of not being on dialysis themselves or having undergone transplants, truly be inside. They were not there as participants; they were there as observers. They are in some senses insider-outsiders, liminal in their own way, perhaps, not really being part of the world they inhabited for so long, but also



involved too deeply to be outside any longer. They know what they saw, but they do not know what the people whom they witnessed suffering experienced or thought.

Faber et al. (2003) and Russ et al. (2005), in their studies on dialysis, experienced the same phenomenon, although on a smaller scale. Their biases (that dialysis was scary and unpleasant) prevented them, in my view, from fully understanding their interviewees' statements. On one occasion an interviewee referred to his dialysis line as an umbilical cord (Faber et al., p. 160) and the researchers expressed horror that any adult should have to lead a life so dependent on external devices. I used to refer to my dialysis line as an umbilical cord too, not to demonstrate my lack of freedom, but rather to show how important it was for me and how much I appreciated it. I discuss this further in Chapter 5. My dialysis line made me feel safe. I expanded my life line image to include other life lines too, so I could feel like an astronaut or scuba diver, with a line to sustain me while I went on adventures and did exciting things I certainly couldn't do without it. Images can be polyvalent. Qualitative research is often too linear or too literal about this.

### *2.6.2 Liminality/littorality in chronic kidney disease*

Some questions remain in the literature on kidney failure and transplantation: How am I perceived? Am I "well", am I "ill", or am I part of a "remission society" (Frank, 1995)? Maybe transplantees need their own "society". We are not in remission exactly. What is the difference for patients between dialysis and transplant, if, from a medical perspective, they are performing the same, or a similar, function (both are therapies, neither are cures)? How are transplant recipients seen? Am I seen as a type of Frankenstein's creature, alive through being made up of dead people's body parts? Am I seen as partly someone else or a whole new person? It would seem that, true to postmodernism, the old binaries of well/ill no longer apply for organ transplant recipients.

Underlying these questions is an issue that writers, both researchers and people who have experienced ESRD, are wary of discussing: coming to terms with a liminal life (Crowley-Matoka, 2005). This is painful for people because it is difficult to define and does not allow one to escape back to being well, which has a better social status, fits better with medical narratives, and offers more security and legitimation. Trying to escape liminality can lead one either to identifying with being "ill" or with failing to be "well", both of which are depressing, disempowering and not entirely accurate.

Liminality, already difficult to cope with, is not always adequate to explain the experience and perception of kidney disease and transplantation. Because the in-betweenness of kidney disease can be long-term, other ways of approaching this may be more useful, because they



will allow people more scope in which to define their identities, come to terms with the complexity of their situations and to accept that an in-between identity is legitimate too. For this I prefer the term “littorality” for reasons discussed in Chapter 1. An existence that is liminal in part may also have elements of littorality and vice versa. For instance, Russ et al. study (2005) centres on older patients having death deferred by dialysis. I see the dialysis experience of these patients as littoral in that this is now their life, but it is also liminal in that dialysis is a waiting room before an inevitable death.

### *2.6.3 The heroic trap and cultural reproduction*

The complexities of both littorality and liminality can be avoided in various ways, such as by falling into the heroic trap or by reproducing certain cultural norms. These challenges are apparent in the different genres (and even in blurred ones) (Denzin, 2009, p. 125). I think they are linked. Reproducing a medical narrative is remarkably easy to do, but it does not tell the complete story. Nor does a personal narrative, but it tells a story that a medical narrative cannot. One is not merely a vehicle for one's condition, nor is one a statistic. Even if one avoids the medical way of looking at one's own life, one may still reproduce other cultural phenomena. The Romantic hero and his/her story are cultural phenomena, for instance. When one tells a story in which one casts oneself as the hero overcoming odds, one is performing a cultural act, even a cultural ritual. With illness narratives one is often expected to take this stance.

Of course one is a member of one's culture and it is not wrong to enact its rituals. But one needs to be aware that they can circumscribe one. One of the chief reasons I waited twenty years to tell my story is precisely because I felt restricted by the types of story that were made available to me. One of these was of the hero overcoming odds. When I was ill this was a useful story, because it gave me something to fight for and I needed to fight to survive. I couldn't afford the luxury of too much introspection, because that would lead to feelings of loss, fear and depression, and these would make it harder to survive.

But a Romantic hero is an archetype and conventionally a man. I am neither. Yes, I fought with everything I had to survive and I succeeded (for now). I got the right kidney, it would seem. Like many heroic stories, my heroic story has an element of almost divine intervention. The gods must have smiled on me that day the nurse and social worker found me at university, in a pre-cell phone age, when I had no pocket pager and no schedule. They walked into the huge library intent on finding me and bumped right into me at the new book stand. It was fated. Heroes are special, you know, and deserve special treatment.

But in our weary, wary and cynical postmodern age, the nurse and social worker's finding me despite the odds may not be miraculous, but rather a random coincidence. After all, why would I be more special than the 45-year-old arc welder or the single mother of three? I do not seem to have displayed any remarkable tendencies since then and have led a rather hidden life. I have not swum the Hellespont or slain any monsters. I have instead taken a job in academic development and live in a small house with a wooden fence, paying my taxes, my mortgage and my credit card instalments.

Being the hero is in some ways akin to being the master of one's fate. Being a master of your fate, however, does not require divine intervention. In fact, it seems to require the absence of it. People today like that. We like to feel we are beyond primitive and childish beliefs in such things, when instead we should praise our own wonderfulness. Nonetheless, being a master of one's fate does require a belief that one is somehow different from the herd – special. For some reason, that specialness is never ascribed to random chance, but rather to one's own choices and actions.

Going through so much intense illness and its effects on my life, my family, my future, I found it extremely difficult to identify with either the heroic or fate-master stories. I did not feel as if I was the master of anything. I had become ill as a baby and had grown up in increasing debility, over which I tried to exercise control through following the prescriptions of my doctor regarding medication and diet. These delayed kidney failure, but could not prevent it. I did not really have much control at all and relied on doctors for medical advice. I didn't have any special insights into my condition. I was faced by huge obstacles and had to engage in desperate battles to survive. But so were many other people. I fought alone. My mother fought too, but we had different battles to fight. She was fighting to save a child; I was fighting to save my own life. I did not choose organ failure and nor do the many other people who experience it. I was hardly unique.

A methodology exists that can help one avoid cultural reproduction that can obscure the individual's experience. Autoethnography concerns an individual in an environment. In autoethnographic narratives, the repair to the self does not only benefit the individual, but also attempts to address the communities to which she belongs.

## **2.7 Coming to autoethnography**

### *2.7.1 Another way of blending genres and roles in illness writing*

Autoethnography is a methodology that allows the researcher to write about his or her own experiences. This has profound implications for illness narratives and research into the

experience of illness. Carrying out research in this way allows a transparent, reflexive way of coming to understand experience, narrative and identity.

Some of the first instances I encountered of autoethnography were illness autoethnographies. Sparkes (1996) writes movingly of the changes in his identity as an active, able, sporting man to a man who seems not to fit in any longer after developing serious spinal problems. He discusses the relationship between his own private identity and his more public, work-related identity, and how these identities are partially constructed by others. He also illustrates the complexity of an identity that will forever more be in-between, as a man who is no longer considered “manly”.

Cook (1996) playfully deconstructs medical discourse in order to re-author her life after serious illness and being subjected to invasive medical procedures. However, by the end of her chapter, she can only “talk back to power” (Pratt, 1992). She cannot truly reconstitute her identity and this is what makes her autoethnography so powerful: she enacts the powerlessness of the patient. Similarly Weitz (2001) gives a nuanced study of an experience so painful that it is almost unspeakable and Rier (2001) gives an account of being in high care, but unable to help himself.

Ettorre (2005) does an autoethnographic study of thyroid disease, whose symptoms can be very nebulous. This methodology is useful in capturing that quality and her resulting disquiet and silent disablement. Temporary disablement is also the theme of Oakley’s (2007) philosophical study of her own experience of a badly broken arm, altered boundaries and all the ramifications of that, social, professional and economic. While she does not describe her study as autoethnographic, it fulfils many of the criteria I discuss in Chapter 3.

A book-length autoethnography, possibly the best-known autoethnography of all time, is Ellis’s (1995) *Final negotiations: A story of love, loss, and chronic illness*. Ellis uses autoethnography to trace a story of two lives irrevocably altered by a fatal disease. The length of her autoethnography allows her to explore many of the complexities and messiness of this situation in a way that a shorter study would not.

Pratt (1992) describes autoethnographic texts as “heterogeneous” in that they can address two distinct groups of readers, the dominant group as well as the marginalised, and can be received “very differently by each” (p. 7). Possibly the type of narrative I am writing could go part of the way to closing the communication gap between the professionals, the patients and their friends and relatives in the renal impairment arena. It will show what it is like living the life, feeling the feelings, rather than taking notes about it. It will also show what it is like living in

limbo, with an invisible “disability”. I have chosen to use my own story because I do not want my voice mediated. I hope to avoid the “problems of appropriation that so often distort and undermine collaborations between nondisabled academics and ‘their’ disabled informants” (K & Duncan, 2006, p. 291).

### *2.7.2 Autoethnography and postmodernism*

For someone to be able to explore what their identity may be and to be able to explore what their narrative is requires a certain type of emancipation that I find missing from many of the renal texts I have discussed in this chapter. This emancipation involves the putting aside of a particular way of reading and writing and accepting instead truly blurred genres, the power of the insider voice, the importance of process and recursiveness. Such a writer would need to accept that a narrative does not naively replicate a pre-existing experience, but instead interprets it and reinvents it, that the act of writing and indeed of reading is an experience in itself. In a world where people are surviving longer because of advances in medical technology, the misuse of terms such as liminality and littorality can prevent them from narrating their own lives and remaining narrated by others. This writer may have to accept that his or her existence is littoral, that he or she inhabits the third space (Garber, 1997). This writer would need to become a type of postmodern narrator.

Some autoethnographers express concerns about postmodern (or poststructural) approaches to autoethnography. Some of these concerns result from postmodern criticism aimed at autoethnographic research. Ellis (2009, p. 231) describes postmodern criticisms as centring on autoethnography’s being “too realist” and therefore “naïve”. These critics ask for a more performative approach that leaves the self destabilised and problematised and texts messy, non-linear and contingent. An overtly postmodern approach to autoethnography is seldom attempted and even less seldom achieved. Often writers pay lip-service to postmodernism, while reproducing linear narratives.

According to Barthes, “the logical continuation of structuralism can only be to rejoin literature, no longer as an ‘object’ of analysis, but as the activity of writing” (Barthes, in Jefferson, 1986, p. 112). Postmodernism continues this to one or other extent. However, this aspect of postmodern writing seems often to be forgotten. The process or production of writing is as essential to its meaning as its content and, indeed, the two are indivisible, because meaning is produced in how one says something. We can no longer naively assert that writing is merely the recording of data or the reflection of an external “truth”. Instead, a text is not only an artefact, but it also has an autonomous existence from the experience it is allegedly recording, so much so that a text can be seen as being a new type of experience altogether. This has

profound implications for qualitative research, but a particularly powerful impact on qualitative research into the experience of illness.

Autoethnography poses some interesting questions about representation, especially in terms of subject/object dualism and mind/body dualism. In autoethnographic writing one can be both the subject and the object of a narrative. One can choose one's identity to an extent. What does it mean to be both subject and object? If one accepts one is both subject and object, is one not still subscribing to a Cartesian mind-body dualism? Can this situation be escaped from through writing about embodiment, or does this reveal that as autoethnographers, and indeed as representers and representees, our responsibility is to continue to question our position(s) and to avoid settling into complacency? If one can achieve this, as is hoped for in this dissertation, one's subject/object positioning and mind/body relationship will remain dynamic, fluid and individual.

In addition to this, writing the ill self when well allows one to incorporate otherness to express a more complex self. This self, a mixture of past and present, can express liminality and littorality residing in one's identity and can also express dualism. As I shall demonstrate in Chapter 3, there are many ways of doing autoethnography. The narrative that emerges needs to convey accurately something of the experience. If the experience is non-linear, messy and contingent, fraught with ambiguity and in-betweenness, the narrative will likely be the same.

### *2.7.3 Consequences of falling between stories*

Postmodernism has caused us to fall "between stories" (Denzin & Lincoln, 1998b, p. 425). We have lost conventional and traditional narratives and we have not replaced them, because in a postmodern world we cannot. This reflects my problems in telling my own story and shows why I eventually, 20 years after the events that spawned it, started to tell it as autoethnography.

I was never able to tell my story of what happened during ESRD, dialysis, transplantation and afterwards. Different types of story existed, such as the "organ transplant solves life's problems" or "chronic illness took from me, but also gave back" or one or other type of redemption, restitution or tragic narrative. However, none of these glib-seeming types really were my story exactly. When I first had my transplant, people I knew wanted to know what had happened and so I told them in terms of the narrative with which I was most familiar – the medical narrative of my doctors that they recited over me for so many years – about creatinine levels, blood pressure, prognosis. But this story seemed to lack something significant: me. I soon learned that certain audiences expected certain stories, the sorts I have mentioned (Weingarten, 2001).

But still I felt dissatisfied with my options, constrained by what I could and could not say, but unsure of how to tell anything else as I had seen nothing else. I was between stories myself, in a type of littoral zone, or maybe even a liminal one, because I withdrew from telling stories in order to prepare to return to telling them.

I also withdrew from the transplant community, determined to live my life free of the constant reminder of my condition. I learned how to pass as “normal”. This was a gradual decision, but made easier by my looking “normal”, which not all transplantees do. I forgot about being a transplant recipient and the long years of medical treatment, despite taking my medications every day and attending clinics at Groote Schuur, the main state-owned hospital for Cape Town. That was “medical stuff” in my mind, not my story, but a type of emotional tax I paid in small amounts every day and in one large submission once a year, for being normal. I compartmentalized my medical condition.

But nothing in life is compartmental. One day the compartment I had attempted to erect burst open. That was the day I discovered I had not qualified for health insurance, as I explained in the Foreword to this dissertation (see also Richards, 2007). My paradigms exploded and so did I. It was nearly 20 years after my transplant and I found that I was still between stories. But this time something was different: after all those storyless years of silence, I found I could not stop speaking. I was like Rosaldo (1989, p. 49), learning about grief and a head-hunter’s rage against a backdrop of Ilongot culture: “One day the fog lifted and the words began to flow: It seemed less as if I were doing the writing than that the words were writing themselves through me”.

My dissertation takes up the challenge of bringing an insider’s view to kidney failure, dialysis, transplantation and life afterwards. The aim in doing this is to show in more detail how a person who has been through this complex situation experiences it and how this affects her identity, as well as to show how this might be expressed in writing. A preliminary narrative I wrote a few years ago had already shown how much there is to explore in terms of a post-transplant experience of identity (Richards, 2006). A pattern of seeking an appropriate and satisfying identity has emerged in recording only a few of my own post-transplant stories. A strong sense of being in limbo or, at any rate, in a liminal state, runs through the preliminary document, combined with a sense of frustration and recognition of not being categorisable. This is to be expected in a narrative about the experience of an orphan disease in an orphan genre. I aim to bring some of the themes from my initial narrative on post-transplant life into these sections about living with a chronic illness from infancy, kidney failure and dialysis.

This type of narrative approach would be more accessible to lay people and would allow them access to other important resources as they attempt to make sense of their situations. It would fall somewhere between narratives such as *Zip, zip, my brain harts* (McDougall et al., 2006), which is aimed primarily at a lay audience consisting largely of care providers, and Siyabulela K's story, which is aimed at an academic one (K & Duncan, 2006). Both of these narratives perform a type of advocacy that is essential in developing a more holistic environment for people with disabilities. Neither, however, concerns kidney failure, transplant or recovery from disability. *Zip, zip, my brain harts* (McDougall et al., 2006) is a story about children with disabilities and how this impacts on the family, while Siyabulela K's story (K & Duncan, 2006) is a collaboration between a man who has schizophrenia and an academic who is writing about it.

I began my quest in a utopian mood, not to say a Romantic one. I was soon to discover my mood changing to one of irony as I found myself replicating the very heroic structures that I scorned in others' stories. I needed to study this phenomenon. As I pursued an investigation of how narrative worked, and specifically how illness narratives functioned, I discovered autoethnography.

## **CHAPTER 3: AUTOETHNOGRAPHY AS METHODOLOGY / METAMORPHOSIS / MÉTISSAGE - WRITING IN THE THIRD SPACE**

### **3.1 Introduction**

One of the things I want to achieve in my research is a narrative suitable for a life-long condition, where littorality, disjunctures in identity and mixed genres are acceptable. In short, I want a narrative that reflects my experience as a long-term, kidney transplant recipient. I also want to understand why my narrative looks as it does and to be able to accept the ironies, contradictions, tensions and paradoxes. I want to be able to capture the complexity of such a long-term experience. I have not seen this represented anywhere in any of the literature I have read. I found this disquieting because it made me feel as if I were invisible and unheard. More chillingly, it made me feel like an endangered species. I have always been aware of the length of time people keep their transplanted organs (and their lives). We renal folk love numbers – our creatinine levels, the length of time we've had our kidneys (the new ones). I have not been able to avoid noticing that most people do not seem to keep their kidneys very long.

There are relatively few of us who have kept our kidneys for more than a decade, even fewer for more than two. In fact, when I looked up articles on long-term kidney transplantation, I found few in all my research and in them "long-term" is generally defined as five to nine years (McCauley, 2004; Stegall, et al., 2011). It seems not enough of us are around after that or too few kidneys have survived to warrant further research. I stopped looking for more information at that point, I realise now, with the same dreadful cheerfulness ("Oh well, never mind, on to better things!") I assume in the patient support group when one of my friends no longer comes to meetings. I no longer ask where they are. I learned long ago on dialysis that their absence usually means they are dead and that the staff won't always tell you what happened. Research seems to indicate by its absences, hiatuses and silences that there is nothing after nine years.

A person who has survived a life-threatening illness for so long, who has a second chance at life, can feel she is living on borrowed time. A person whose life is filled with texts can feel disquieted if her story is nowhere among them. "Life comes to us in the form of stories, articulated through storytelling" (Gubrium & Holstein, 1998), after all. If you have no story, you may even feel that you have no (legitimate) life. Superstitiously I decided that if I could write my story and understand it in intellectual terms, in an academic context, even tell it to others, have it become part of the body of knowledge, I would not feel so endangered. My longer story and I would gain a type of credibility because we would be endorsed by research. Previously,



as a new transplant recipient, I had been hindered in telling my story because my story did not fit with others I had heard and therefore seemed as if it had no place or right to belong (Garden, 2010). Being able to tell a story that reflected my experience and not one approved of by others whose circumstances differed from mine was something I hungered for.

For one thing, I noticed during my reading that liminality is a problem for people experiencing illness, either chronic or acute (Cojocar, 2007; Crowley-Matoka, 2005; Little et al., 1998). I do not find liminality disturbing; I find the incorrect use of the term disturbing. In a chronic, life-long condition, an identity in flux and inhabiting a littoral zone is simply how things are. I have become used to it over the past two decades. Now it is simply who I am. I do not battle with the subjunctive mode (Good & Good, 1994). I maintain that sometimes and at some points in chronic illness, one should embrace one's in-betweenness, rather than trying to do away with it, and instead inhabit that littoral zone, because that is how one's life is.

And so I chose autoethnography as a methodology for very specific reasons: it would allow me to write an academic and personal narrative together; it would allow me to work with liminality and littorality; it would allow me to consider for the first time the ironies, contradictions, tensions and paradoxes of my story. This is partly because autoethnography is not only a methodology, but also a means to changing one's identity by occupying an alternative space from the binary positions that are usually available to one in a world where one is other than the norm.

### **3.2 Autoethnography as I use it in my research**

Methodology is a claim about the significance of the theoretical underpinning of the study, not necessarily a recipe that allows a study to be replicated or that separates researcher from object of research, which is not possible in postmodern research (Clandinin & Connolly, 2000; Clough & Nutbrown, 2007; Jones, 2005; Nelson, 2001). Autoethnography is a type of conduit for a consideration of a certain type of experience. In some ways the work of autoethnography is similar to that of bricolage.

Far from generalising findings, the bricoleur is more concerned with specific findings and what these reveal about a specific study. Turning autoethnographic method or bricolage into dogma would be tantamount to what Chamberlain (2000) refers to as methodolatry and would run counter to its theoretical underpinning. Sensitivity to the context of analysis and the specific ontological and epistemological conditions that produced it can only derive from dialogical research (Kincheloe, 2001). Any truly reflexive research is dialogical even if paradoxically it contains only one voice.

Autoethnography is the focus of this chapter, in the sense of how and why narrative would be used as a strategy, tool or process, rather than a way of collecting data when researching and writing illness narratives. Autoethnography takes different forms and I shall discuss how various researchers see different types of autoethnography in order to position my own views. In addition to being able to take different narrative forms, autoethnography can take forms such as performance autoethnography, poetry, sculpture and more (Denzin, 2009; Martineau, 2001). I cannot discuss all variants of autoethnography in this chapter. I shall restrict myself to written texts. I discuss the rationale behind autoethnography, its advantages and limitations, and its relationship to writing about illness, as well as my own approach to autoethnography in my doctoral research. For the purposes of this chapter I shall restrict myself as much as possible to a discussion of autoethnography in research about illness. The field of autoethnography is large and varied. It has proven particularly useful in health research and education studies.

Inherently postmodern, autoethnography is a tricky subject and a subtly textured term. It is protean in its practical applications. Couser describes it as “a slippery, ambiguous, but useful – indeed indispensable – term” (2009, p. 93). I see autoethnography as a blend of hermeneutics and bricolage: “If hermeneutics came to connote the ambiguity and slipperiness of textual meaning, then bricolage can also imply the fictive and imaginative elements of the presentation of all formal research” (Kincheloe, 2001, p. 680). Part of autoethnography’s slipperiness lies in its deceptively everyday aspect: telling stories about human experience. Another part of its difficulty lies in its postmodernity. Possibly more than any other qualitative methodology, it is by its nature a conduit between different aspects and methodologies of research. This makes it intrinsically postmodern. If researchers do not appreciate what this means, they will not understand how it can and does function.

The core of this chapter concerns the conceptual changes brought to narrative in the postmodern era and includes the work of Richardson and St. Pierre (2005), Ellis (1995, 2004, 2009) and Frank (1995, 2000, 2002, 2007), amongst others. Most importantly, autoethnography changes a basic perception about research. The traditional distinction between writing (as a means of recording) and fieldwork (as a means of researching) is the underpinning of much research (Clough, 1998). In the spirit of Van Maanen (1988), Richardson and St. Pierre (2005) problematise this distinction, showing that writing, far from being part of data tabulating, is very much part of the discovery process of research itself and that writing affects the meaning of one’s ideas, a far from transparent act.

The personal story as a source of experiential data has caused a great deal of perturbation in qualitative research. This perturbation stems partly from the recognition that personal

narratives do not offer “unmediated access to experience”, nor can experience be conveyed “in some pristine or authentic form” (Gubrium & Holstein, 1998, p. 163). That is not the purpose of an autoethnographic narrative. Rather, it can be seen as a form of social inquiry with human actors in a human context, rather than being about human action (Larson, 1997). I write from the premises that an understanding of that narrative is a cultural act and is shared, that no story is independent of its culture or of a larger narrative.

Autoethnography is a quest, whether for self-esteem, identity, recognition or anything else. This quest is, however, a specific sort of quest that involves not only going forward, but also going back and looking again – re-searching – and for this reason, an autoethnographic narrative may not take the typical form of a quest narrative as described by Frank (1995) and others. Autoethnography is highly concerned with self-perception. This aligns it with current trends in disability studies (preventing othering, empowerment, visibility, having a voice). The reflexivity of the researcher can be difficult to explain or convey (Hertz, 2006; Mayan, 2009). Is this useful to research? I find it is essential, but how you convey it can affect the seriousness with which your work is viewed.

Because the quest is an exploration through writing, researchers have been suspicious about postmodern hermeneutics, wondering whether anything lies beyond textual prank-playing and pyrotechnics (Marcus, 1998). They have seen that writing can conceal rather than reveal. Texts can “enchant”, concealing information and seducing the reader. They can seem to offer more than they actually have to offer, like access to truth and understanding. They are like faerie gold or a changeling child, who is not quite what he appears to be. One may forget that long ago changelings were not evil tricksters. Once faerie children and human children could change places for the betterment of both their races (Anderson, 1998). Likewise, people may forget the purpose of written texts. They are not meant to stand for external reality or to be the truth. They are a means of moving towards it.

### **3.3 Postmodernism, autoethnography and identities in flux**

The goal of qualitative research is not generalisability or quantifiability. Instead, it is to offer a more complex, deeper, textured view of human subjectivity, to capture some part of human experience and to reflect on it, to try to understand its philosophical underpinning (Denzin, 2009; Goodall, 2008; Hollway & Jefferson, 2000; Richardson & St. Pierre, 2005). The postmodern period has forced researchers to reconstitute the research subject (Hollway & Jefferson, 2000) and even themselves and their relationship to that subject (Fontana & Frey, 2005; Hollway & Jefferson, 2000; Van Maanen, 1988). Hollway and Jefferson describe the

type of nuance that is required as “everyday subtlety” that is often lost from research (2000, p. 2) and whose loss can result in essentialising categories.

A goal of postmodern qualitative inquiry is to try to avoid essentialising categories. Certain postmodern, so-called postcolonial researchers and writers, such as Glissant (2002), Mudimbe-Boyi (2002), Pratt (1992) and Spivak (1988), would very strongly support questioning authority and trying to reveal and destabilise power structures, overcome dogma and question the status quo. Ultimately seeing the common humanity between researcher and researched is like understanding that as important as the country club is to “us”, most people do not belong to it because they are kept out, with all that entails about access to power and resources. Recognising that allows researchers to see that people are not resources or subjects, but fellow minds, with experiences and insights to contribute. These days blurred borderlines and borderlands are almost unavoidable in the light of the massive social and economic changes in the world and the realisation that research can play an important part in giving a voice to disenfranchised people and redressing wrongs (Denzin, 2009). Some researchers inhabit both the world of the researcher and the researched. I am one of these. I am studying my own experience and I am doing it not only to empower myself, but also to empower others who have lived in the strange post-transplant world. We need other stories and we need to tell them.

Postmodern narrative inquiry is especially concerned with the “third space” in and between polarities or binaries: researcher and researched, subject and object, past and present. Beyond “knowing how” and “knowing that”, there is a third kind of knowledge, “knowing what it is like” (Goodall, 2008, p. 14). Narrative creates “an alternative pathway to meaning” that is both “imaginative *and* analytical” (Goodall, 2008, p. 14). For Goodall, narrative is the epistemic. The quest for knowledge becomes the act of knowing. Many autoethnographers would agree (Ellis & Bochner, 2000; Poulos, 2006; Richardson & St. Pierre, 2005). Some would not (Chang, 2008).

A movement from scientific objectivity to radical subjectivity is the natural progression in this type of research. There are varying degrees of subjectivity in postmodern research (Ellis & Bochner, 2000; O’Byrne, 2007). Postmodern autobiography problematises the “notion of the coherent, individual self”, while postmodern ethnography problematises “the realist conventions and objective observer position” of traditional ethnography (Reed-Danahay, 1997, p. 2). Autoethnography combines aspects of both of these.

Autoethnography has the potential to be creative and flexible because, like bricolage, it can blend different qualities of research in different ways. It can help create a non-linear aspect to

a linear academic argument. The non-linear aspect may be a more accurate representation of how life works. Wyatt's (2008) autoethnography about loss illustrates this performatively, through being itself a recursive, fractured and fragmented text. The very act of making a story (and, indeed, living one) concerns structure and antistructure in Turner's (1969) sense. Structuring a story is necessary for the story to make sense. The story's centre and boundaries, the way the different parts fit together can sometimes even be seen as mimetic of the structure and antistructure that it represents. A fragmented story depicts a fragmented reality. Illness can, after all, be seen as "a series of disconnected shocks" (Broyard, 1993, p. 19). Broyard did not like this, but I do. If the experience is a series of disconnected shocks, then it should be shown that way. In the chapters that follow, this is part of what I aim to capture.

The everyday subtlety of life is difficult to capture. Autoethnography has allowed researchers to research elusive experiences or unspeakable experiences: teenage motherhood (Muncey, 2005), loss of a home to a fire (Lollar, 2010), loss of a partner to a slow death (Ellis, 1995), the experience of persistent "minor" illness for an older woman (Ettorre, 2005), the change in masculine identity after a sports injury (Sparkes, 1996). What all these stories tell us is that people battle to understand profound changes to their identities and that their new identities can seem liminal for a very long time.

Autoethnography can help writers to do this by blending the personal with the public, and the emotional with the intellectual. It is one thing to know that you suffered. It is quite another for that suffering to have meaning. The academic component of autoethnography can take a researcher beyond believing that his or her story has meaning to seeing what that meaning may be ontologically and epistemologically. It can help situate the story in a bigger picture and give it a sense of proportion. It can help a researcher to see how and why their story may have developed and what its influences might have been. Seeing that can help one to develop one's story further (Bruner, 1987; Bury, 1982; Ezzy, 1998; Frank, 2000; Sarbin & Kitsuse, 1994) and to allow one's theories to evolve. Sometimes seeing that your story is fractured can in itself be helpful. Understanding a story goes beyond intellectual appreciation of it, however. Autoethnographers explain this in different ways (Chang, 2008; Ellis & Bochner, 2000; Pratt, 1992; Reed-Danahay, 1997).

Writers have long recognised the restorative properties of narrative in illness and how narrative can heal a damaged identity (Brody, 2003; Bury, 1982; Frank, 1995, 2002; Kleinman, 1988). I contend that narrative can and, arguably, should do more than this. Immediately after acute illness and medical crisis, a narrative can serve a ritual function of creating and defining a liminal space, allowing the narrator to exit an old identity that no longer applies to them and

to learn to inhabit a new one that they might not have expected. However, I contend that a different set of problems and narrative needs await a person who must live and has lived with a long-term chronic condition or with (in my case) a form of therapy that is not a cure, but that allows me to function like a healthy person. The narrative forms that work so well in other circumstances (Brody, 2003; Frank, 1995) no longer apply. Twenty years post-transplant I am not trying to form a new identity in response to crisis, repair a damaged one or obtain closure. I have, over the years, gained an identity of my own that no longer fits categories – or narrative types – imposed by others. I have my own story (or stories) now and I also have my own meanings and routes to healing (Hovey & Paul, 2007).

### **3.4 Métissage: Telling stories in the third space**

The first version of this chapter began as a description of what autoethnography is and ended as a patchwork quilt of ideas drawn from different disciplines. Perhaps a soup or salad might be more accurate, because it is not intended as something to cover something else, but rather as a specific flavour compounded of many other flavours, a bricolage. I was at first alarmed by my strange concoction and explaining it to myself as a postmodern, fractured text in many voices did little to settle my unease. So I redrafted it in various ways, intending to find an underlying structure to my ideas on autoethnography. The problem with that sort of intention is that one tends to find what one is looking for. The structure that now exists may be entirely artificial and not a true representation of the evolution of my ideas on autoethnography as methodology. However, in the course of my struggles I encountered a useful term.

A term that captures the process of permanent becoming and changeability in place of fixed being is *métissage* (sometimes spelt “metissage”) (Glissant, 2002). It is a term that Glissant used initially to give an identity to Creole people. Previously they tended to be represented as deriving from various cultures, but not having an identity of their own, a “defective” representation of the “parent” cultures. *Métissage* allows an alternative identity to emerge – a positive Creole identity, which comes from and yet does not slavishly follow its parent cultures. In the same way, you share qualities of your mother and your father, but are not a replica of either. Instead you are your own person. Such people occupy an alternative space of possibility, the result of blurring binaries, a type of third space (Garber, 1997). Creolisation is not the mixture of two things, but the creation of something “new, unheard-of and unexpected” (Glissant, 2002, p. 291). Lionnet (1989, p. 14) shows some of the implications of this, when she describes “the site of undecidability or indeterminacy” as eluding categorisation by its dynamic nature and its ability to deconstruct and resist “symbolization within a coherent or homogenous conceptual system”.

I see my academic and narrative position as that of a Creole: I am researcher and researchee. Associated with this recognition of my Creole status is the question: what is the academic value of my work? What saves it from being “pointless self-analysis” (Goodall, 2008, p. 39)? Personal reflection must be supplemented by epistemological reflection (Goodall, 2008). Only together can these types of reflection really allow a new identity to emerge. How much of an argument should there be and what form should it take? What about the process of autoethnography? What does it reveal? Should this be discussed or revealed in the course of one’s argument? Concealing the process seems to send one back to the very academic forms one is trying to escape by blurring genres.

Métissage is not just a state of being, but also a practice. This is one way in which one might practice bricolage and autoethnography, because practices of métissage can allow a critical approach that avoids essentialism and anti-essentialism, by acting as “textual and performative strategies in the unsettling of any reductive politics of identity” (Zuss, 1995, p. 170). The focus on essentialising can be replaced with a focus on relationship(s) and multiplicity (Zuss, 1995). One instance is the multiplicity of the narrated self. Portraying the self as contingent and multiple can disrupt narrative form and destabilise positions of power in a text, creating a tension between self-as-subject and self-as-object, in the context of changing experience and knowledge (Zuss, 1995). This dialogical approach to selfhood and identity in a text can be an advantage in understanding what an experience, particularly a long-term one, is like and how it is complex. Using a narrative methodology of this sort allows a researcher to mix, blur or erase the difference between the emic (insider position) and etic (outsiders’ stance) and can produce a deeper understanding of what one is studying (O’Byrne, 2007). This is similar to Kincheloe’s (2001) conception of bricolage, especially his explanation of how the slippery nature of hermeneutics combines with fictive and imaginative presentation.

In addition to this, autoethnographic writing creates a third space between academic and personal biographical writing. This can be seen as type of liminal space, but it can also be seen as métissage. Does métissage help address liminality? Is it especially suited to liminality? Is it a liminal state or a state that appears liminal but is actually different? Is it a state of inbetweenness/becoming? It is all of these. However, I would say that métissage creates a space for liminal identities rather than resolving them. A third space is useful in telling personal stories of illness, because it makes space for the liminal and for one’s change in identity, from researchee to researcher and back again, from a person who may have belonged to the kingdom of the well and has now emigrated, from a person who has changed through doing the research into something she never dreamed of being.



A blending of writing cultures can allow one to be more expressive of one's situation and to capture one's experience in a more three-dimensional way. For my part, I consider the textual nature of autoethnography and the act of writing as a type of *métissage* and a type of third space. The body of the text itself symbolically takes the place of experience, possibly even of the body of the person writing about their illness. Reinscribing a story is not a small thing. It is a powerful ritual of (re)creation. It builds a bridge between writer and reader, past and future, experience and understanding, an old identity and a new one (Pratt, 1992; Trinh, 1991; Zuss, 1995).

In Glissant's words (2002, p. 195): "What might writing mean today? ...it may be, above all, a matter of looking for the frail but trustworthy link between the wild diversity of the world and the balance and knowledge we desire to have." For me the key words are "desire to have". This recognizes that what we want may remain always, already out of reach, but through writing about it, we might write towards it. If we write ethically, we would acknowledge that this is what we are doing, thereby allowing the story to remain in flux and dynamic, and to recognize that it is part of an on-going, larger story. All research is iterative in various ways, but postmodern research, and especially autoethnography, makes this aspect of knowing explicit by the way in which the written text is structured, drawing attention to its self-referential qualities, recursiveness and fractures or disjunctions. Hence writing itself becomes a method of inquiry (Richardson & St. Pierre, 2005) and research becomes re-search and re-vision.

For these reasons the writing aspect of autoethnography cannot be overlooked. Autoethnography is not a matter of transcribing data or even really of representing it, but of interpreting it and synthesizing it. In this it performs a key function of qualitative research (Chamberlain, 2000). What does it mean to write? It means, amongst other things, to take note of, to describe, to record, to inscribe, to fix, to control, to mediate, to authorise. This is an inescapable part of writing, but that does not mean a researcher should be unaware of it. Awareness of this can to an extent create a type of deconstruction, reflexivity and resistance to discourses that control, legitimate, legislate and mediate ideas. "Autobiographical *métissage* is a conscious textual act that resists the fixed categories and ideological closure of racial, ethnic and gender identities and their performance within a culture" (Zuss, 1995, p. 168).

### **3.5 Categorising autoethnography**

On a simple level, autoethnography is telling a story that involves the writer as a character, for example, as a central character who narrates, or as a peripheral observer who is nonetheless involved in what unfolds. It is the way that researchers represent their everyday life (Denzin, 2009). Chang (2008) describes autoethnography as "a research method that utilizes the



researcher's autobiographical data to analyse and interpret their cultural assumptions" (p. 9). Unusual sources can be used for autoethnography such as, for instance, dreams (Poulos, 2009). Autoethnography can take many forms along a continuum that ranges from autobiography to ethnography. However, Chang (2008) warns that telling one's story will not result in better cultural understanding. This can, in her approach, only be obtained through "in-depth cultural analysis and interpretation" (p. 13), which she sees as autoethnography's role. My contention is that this type of understanding can be gained through other means too.

The protean, slippery nature of autoethnography (Couser, 2009) can be seen in the different views of what autoethnography is meant to do. It is an interdisciplinary, multidisciplinary, even transdisciplinary, methodology and different disciplines have different requirements of it. Denzin (2009) and Martineau (2001) describe autoethnography as a type of performance. Denzin finds it useful for symbolic interaction, Martineau for art as protest. Sparkes describes autoethnographies as "highly personalized accounts that draw upon the experience of the author/researcher for the purposes of extending sociological understanding" (2000, p. 21). Theoretical, analytical and ethnographic foci produce a surprising variation of autoethnographic accounts (see Chang, 2008; Pratt, 1992; Reed-Danahay, 1997 as instances) to more autobiographical work from Ellis and Bochner (2000) and Denzin (2009).

Ellis (1998) makes a strong case for the sociological and ethnographic value of using other researchers' written work to create a context for one's own and it is to this view that I adhere. This is "systemic sociological introspection" (Hudak, 2007, p. 59). The personal narrative is combined in various ways with theoretical texts from the social sciences. My contention is that the interplay between these different types of narrative will allow a specific type of meaning to be made.

However, autoethnographies are inclined to have a particular *métissage*-like quality: Jones (2005) explains that autoethnographic texts tend to resist categorisation and closure because of their liminal nature. She describes autoethnography as being "between story and context, writer and reader, crisis and denouement" (Jones, 2005, p. 764) and points to "the power of the in-between", of occupying a space between theory and practice, analysis and action (Jones, 2005, p. 784). This type of writing deliberately reveals tensions, raises questions and recognises the hyphens to which Fine (1998) alludes.

The autoethnographer is a "boundary-crosser", whose role can be characterised as having a "dual identity" (Reed-Danahay, 1997, p. 3). On a most basic level the autoethnographer is both the subject and the object – both the insider and outsider. Reed-Danahay, however, warns that this type of dual identity is too simplistic for an understanding of processes of

representation and power. She also discusses the phenomenon of the teller being one who is not completely “at home” (Reed-Danahay, 1997, p. 4). This allows the teller to re-inscribe and redefine everyday conceptions of self and social. At the core of any autoethnographic study, therefore, are issues of identity and selfhood.

In-between lives, such as those of people who are in one or other type of remission, are particularly well suited to this type of writing, because they play themselves out in two often contradictory worlds – the world of the well and the world of the ill. Furthermore, the tension between being subject and object can serve to highlight aspects of a social situation and to capture aspects of embodied experience. This can also subvert power structures that are often not questioned in other types of discourse.

Richardson and St Pierre (2005) break autoethnography into three components: auto (self, autobiography), ethno (context, ethnography) and graphy (writing). They explain that autoethnographic texts can be individual combinations of these three parts, emphasizing one or more. I would say that researchers embarking on autoethnographic studies would have to ask these questions: How do these different aspects of autoethnography relate to each other? Where do I fit in as researcher and as researchee? I have a certain type of authority as researcher and play a specific role, but I am split in two (or more) pieces, doubled as a subject. Have I subjected myself as any other subject of research? Have I become a postmodern subject, dual and elusive? Or does my “unique” situation make me something else entirely, as both subject and subject (that is, as subject-as-agent and subject-as-object)?

Some researchers emphasise the usefulness of autoethnography in understanding culture(s) and in linking the self and the social (Chang, 2008; Ellis & Bochner, 2000; Hudak, 2007; Pratt, 1992; Reed-Danahay, 1997). Pratt’s (1992) version of autoethnography, for instance, describes the phenomenon as a clash of cultures, a type of cultural dialogism. She draws a contrast between what she describes as authentic narratives of self-expression and inauthentic narratives of assimilation. Autoethnographic writing is a way that colonised people can talk back to their colonisers and assert their identities. Pratt warns against a simplistic, polarised view of autoethnographic writings that ignores their transcultural and dialogical character. Her approach to this is not unproblematic (Zuss, 1995), as I discuss later.

Autoethnographic types vary as they do because researchers use autoethnography for different reasons. For instance, there is a fair amount of autoethnography in studies of educational biography. There are also a number of autoethnographies written on the experience of illness (Ellis & Bochner, 2000). My article makes a case for having some memoirs, for instance, classed as autoethnography (Richards, 2008).

If I were going to study chronic illness, it may help to study how the illness presents itself medically. It would help more knowing how it feels to live it. An example from my own life: when I was in end-stage kidney failure, my doctor told me that “one can live quite comfortably on a third of a kidney”. That was the received medical point of view. Believe me when I tell you there was nothing comfortable about living on a third of a kidney. My experience was that it was slow torture, a hell of endless thirst that no amount of fluid could quench and being tied to a wasting body whose dwindling energy could not drag me from the bed to the shower without going into deficit, experiencing endless exhaustion, and enduring metallic-tasting food. I experienced a deep, ingrained sense of failure because I could not live the normal life I was prescribed. No, nothing comfortable there, I’m afraid. In fact, it is because of remarks like the one my doctor made that I find it important to write this dissertation. I want people to know how it really was. So I need to remember how it was for me, before I remember how my doctor taught me it ought to have been.

Another less subjective, but, ironically, more personal reason for the difference between the two is that a story of an experience of illness is before anything personal, even though it occurs within a community or communities (family, friends, medical care providers). A story of education is indeed personal too, but it is simultaneously communal. You cannot have an educational biography without reflection on specific types of interaction with communities. The ways in which you interact with your communities as patient/healthcare provider or as student/teacher differs. However close you are to your students or teachers, your relationship with them is different from your relationship with your doctors or patients. Students do not depend on you for their physical existence. You do not depend on your teacher for literal help to survive that you cannot get anywhere else, such as access to medicine or life-saving technology.

I have identified three main types of autoethnographic illness narrative: “testimony”, “emancipatory discourse” and “destabilised text” (Richards, 2008, pp. 4-7). Briefly, the three types do tend to overlap, but can be described in terms of their chief functions. Testimony’s chief function is to make sense of damaged lives and to give the author a chance of being understood. Emancipatory discourse tends to have a political or social reform angle. The destabilised text aims not to simplify and control, but rather to free itself from such normalising confines and to remain open-ended, thereby engaging the readers in the debates and struggles of the author and encouraging them to make up their own minds, or to continue to engage with the issues beyond the confines of the narrative.

### 3.6 Autoethnographic challenges

#### 3.6.1 *Methodological challenges*

One of the challenges of autoethnography is that it can be approached in several different ways. For instance, Wall (2006) attempts to trace her own journey of learning to know, while Ettorre (2005) uses her story as a launching pad for an analysis. Both these approaches left me feeling that something was lacking from their work and yet they both gave me insights. Wall alerted me to the highly abstract nature of much discussion about autoethnography and caused me to wonder why this was so. I return to this later in this section. The structure of Ettorre's article made me consider how people use academic and personal writing together. Ettorre chose to separate them. Doing this, however, took her away from what I consider fully autoethnographic writing, because she compartmentalised the genres and did not blur them. The result was a traditional research article that used narrative as data.

Examining these articles revealed some important considerations to me. A significant compound challenge with autoethnography is that a) the person carrying out the research may still value traditional forms of research or be influenced by them, and b) the environment in which she conducts research (a university faculty, a field of study, a peer-reviewed journal) might value and be informed by traditional hierarchies. This is a challenge with any type of postmodern qualitative research (Denzin, 2009; Marcus, 1998), but its implications for autoethnography are profound, as they would undermine the ontological and epistemological foundations of the exercise. The privileging of analysis over experience submerges the embodied life once again.

Doing this, one might (re)create a hegemony or dogma that merely asserts itself without insight or self-analysis. In addition, any intellectual endeavour is invested in protecting a dominant ideology to some or other extent and of normalising this dominant perspective (Derrida, 1988; Foucault, 1975/1991). One has to speak the language of power to survive (Spivak, 1988). Autoethnography attempts to address othering in various ways, including allowing the researcher to be transparent about his/her relationship with what s/he is studying and/or being the subject of research as well as the researcher. Nonetheless, autoethnography can replicate the very power structures it seeks to challenge by replicating traditional academic discourse. It is easy to privilege academic discourse over "other" discourses – in the end I must produce an academic document that has intellectual worth in a specific context to be awarded my degree. Nevertheless any academic research in the postmodern era should include a humble acknowledgement that one does not have the last word. Of course, the trouble with humility is that as soon as you think you have it, you lose it. The tension between

experience and analysis needs to be sustained. Neither the academic discourse nor the experiential voice should dominate, if this new *métissage* is to be sustained in a text.

When representing the Other (whether it is oneself or someone else), there is a tension between the value of raw experience and analysis. Raw experience can, out of political desperation<sup>3</sup>, become privileged over analysis (Fine, 1998). Fine is not talking about autoethnography specifically, but what she says can be applied to autoethnographic writing, which can become an excuse for avoiding rigorous intellectual dialogue. The “conception of what cannot be said” can become a way of permitting lazy thinking – it is the same as saying that something is difficult to conceptualise, therefore I will not try.

In addition to this, a search for identity and autonomy can become so desperate and emotional that it can cause one to be persuaded that Creolisation has resulted in something unique, not just a mix of things already known. The supporters of the idea that Creolisation results in something unique are almost invariably people whose identity is, in one way or the other, Creole. Despite this, a person or an idea or even a text may remain a child of two cultures, resembling both, but never truly taking on his/her/its own identity, an uneasy mix of oil and water.

Reinscription and the replication of methods or of technologies is pervasive and difficult to avoid (Denzin, 2009, p. 187). Buzard, for instance, points out that Pratt’s approach to autoethnography does not deconstruct its own problematic metaphors of “Voice”, “Letting the Silenced Speak” or “Talking Back to Power” (1999, p. 9) and, as a result, unwittingly entrenches the dominant ideology’s construction of the Other as other, lesser, weaker, and so on. It is difficult to deconstruct one’s own ideas. After all one has constructed them so painstakingly in the first place. The human mind likes to categorise ideas. We like to know where things belong. We like ritual, where everything has meaning and everything has its place.

One of the greatest challenges I faced in writing this chapter was whether to write it recursively or in a linear way. Eventually I came to see that I would have to write it recursively if I were to be true to the ethical and intellectual considerations of my research. However, this meant that I would rearrange the traditional order of a dissertation, because I would have to include some of the discussion and conclusions in the methodology section. This could require my readers to jump back and forth in the dissertation to see the full picture. On an aesthetic and more personal level, I was reluctant to write this particular section recursively, because I believed it robbed my dissertation of the element of surprise. I had intended to lay out the methodology

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<sup>3</sup> This can be seen sometimes in disability studies or in research whose aim is to empower minority groups.

and then reveal how it worked in practice and discuss the implications, even though a dissertation is not traditionally supposed to surprise. My research surprised me and so I decided that some of this surprise should be captured methodologically. The blurring of personal and academic narrative genres allows – even insists – that this happens, because personal narratives allow truths to emerge in a different way from academic (linear) narratives.

Academic writing is by tradition linear, because of our Cartesian belief in rationalism. Rationalism and rhetoric (in the sense of rational argumentation), as Vico argued, are not always in accordance with one another, although both aim at the truth (Struever, 1983). While Descartes saw the human mind as objective, Vico maintained that we construct our view of the world through our own contexts, meanings and symbols (Van Oorschot & Allolio-Näcke, 2006). This is a central problematic in writing up research, even in traditional research. In traditional research, although one's research journey is (or should be) recursive, one writes about it and its methodology in a linear way. In so doing one achieves an impression of mastery – one has been through the experience and streamlined it. In the type of research I am conducting, the problematics of methodology are as central to the dissertation because they are also the findings; they are the testing of the theory. The struggles I had with various aspects of postmodern qualitative research are as crucial to the theoretical underpinning of this project as were my struggles in recording and arranging my narrative. For this reason I decided to incorporate some of my discussion of the method in this chapter. More follows in subsequent chapters and in the conclusion.

Life is not static or easily divided into binaries; instead it is messy and contingent. Ideally autoethnography is a way of attempting to capture some of that messiness, multiplicity, relativism and changeability of identity. Buzard asks a crucial question concerning colonised people writing back, “but do they have to be trapped in the place from which they begin to speak?” (1999, pp. 9-10). Surely part of the point in speaking in the first place is to break out of the colonised space and to create a new identity of one's own? O'Byrne's (2007) assertion that stories are eternal and speak where memory cannot is worrying if these stories trap people in places that are disempowering. Possibly we should instead consider that stories are dynamic, changeable and constantly in flux. If we tell them long enough we either repeat them and entrench our own disempowerment, or we discover that they are growing and changing, and so are we.

Connected to this is the issue of ontology and epistemology. If you write without sufficient reflection or you write without sufficient reading, you run the risk of not understanding your O's and E's (Chamberlain, 2000). That is a risk in any type of qualitative research, but especially in autoethnography. The aesthetic features of the writing can stifle the philosophical dimensions.

Two autoethnographies I have read fall into this trap. They both concern a quantity of poetry mixed in with more theoretical work. The mixture is uneasy and does not result in *métissage*. In one autoethnography (Clarke, 1992), the researcher is a mother with an asthmatic child. She uses Audrey Lorde's poetry to express what her own words cannot. While reading her article I found myself distracted by the poetry, partly because I am certain Lorde was not writing about asthma and partly because the excerpts distracted me from Clarke's own insights. She could have left the poetry out and her article would have been more forceful, because it would have been in her voice and more about her and her daughter.

Similarly, in an article about eating disorders, Tillman-Healy (1992) uses poetry to convey immediacy of experience and emotion. This time the poetry is by the author, but it nonetheless serves to distract, rather than to enlighten, appearing in the text seemingly randomly. In both cases, the poetry excerpts are longer than is necessary to illustrate any of the points raised and so they scatter the focus and break up the texts, but not, as far as I can see, to achieve any postmodern effect or comment on identity and change. My impression was that both writers included poetry to illustrate what they felt, but they would have been better served by writing out in prose what they felt, even though they might have found it painful and frightening. That way, they might have been able to use narrative to express what they meant or even to change their stories. Instead, the poetry becomes a way of distancing the reader and the writer from painful and powerful emotions, because it breaks the narrative flow and is cryptic and metaphorical (and hence difficult to read). If one simply writes in a personal style and also in an academic style, one runs the risk of creating a patchwork text, instead of something new. The new text might not necessarily come from the dialectic between personal and academic.

Methodology itself can be reified or replicated, leading to methodolatry (Chamberlain, 2000). This is what Glissant (2002) calls fixation, transcription or inscription. The balance between fixing a methodology to ensure quality and rigour, and denying it appropriate adaptability is a fine one. Couser (2009), despite his concern that amateur ethnographic biographers lack rigour and theoretical underpinning, acknowledges that much academic work can be overly theorised and abstract. Autoethnography is, by its nature, an adaptable methodology. Because of this, it ought to produce highly specific and concrete narratives. Couser (2009) wants to try to pin autoethnography down and categorise it, but it becomes slippery, because of its subject matter, existing in the blurred boundaries and intersections of individual identities. Autoethnography is slippery precisely because of what it does: adapts, individualises, blurs boundaries and subverts categories.



For this reason, one of the largest gaps in autoethnographic research is examples or descriptions how one might carry it out. Writing about autoethnography can seem highly abstract or theoretical (Wall, 2006). Such writing (examples include Chang, 2008; Ettore, 2005; Oakley, 2009) is often autoethnographic, but may give the impression of only being about autoethnography, because autoethnographies are often unique and do not follow a pattern and the form and the content have a dialectical relationship with one another, which is often overlooked. If one reads an autoethnography in a conventional academic way, as a linear recording of objective, external facts, one risks missing part of what the writer intends. The writing is not a recording of an external truth, but rather the construction of an experience and a passage into awareness about that experience, however transient.

As I discussed earlier, an important aspect of autoethnography is that it consists of “auto”, “ethno” and “graphy” (Reed-Danahay, 1997). Ellis and Bochner (2000) point out that in practice one or other of these options is privileged. This does widen the scope for what can be produced, but also opens the door for sloppy and superficial use of methodology. While I do not want to make the method too rigid and perpetrate methodolatry (Chamberlain, 2000), in my opinion the “graphy” part is often overlooked.

As autoethnographers go, Chang (2008) comes close to methodolatry. Her fascination with formalising the method and creating something solid is almost quantitative and she seems not to have addressed the deeper epistemological and existential issues in her study. Exchanging one system for another can all too easily lead not to displacement, but to re-placement. The new system becomes as totalitarian as the old. I suspect one of the challenges of writing autoethnographically is that too structured a methodology would create a dogma that might limit one. “Narrative smoothing” (Spence, 1986) might occur that would deprive the autoethnographic narratives of their contingency. Interpretation cannot be formalised (Denzin, 2009). It must pertain each time to that which it interprets. It has to be specific, not universal or general. Denzin is not referring specifically to autoethnography, but to postmodern research methods that attempt to address the issue of how to avoid othering. No one can afford to be complacent. I find Denzin’s point about interpretation especially pertinent to autoethnography, which is all about the specific and the individual.

A variant of this is essentialising researchers’ identities, which can be extremely tempting and detrimental to this type of research. Polarising and essentialising identities deprives one’s ideas of nuance and prevents one from seeing internal conflicts and tensions within a group and even the “overlapping, conflicting, decentred circles of identities” themselves (Fine, 1998, p. 148). We all enjoy multiple identities and these identities overlap; in my case, as researcher and researchee, in others, such as Fox and Swazey’s (1992) version of “insider” researcher,



as outsider-insider. There are many other combinations. Just as it is essentialist to assume that “only women can/should ‘do’ gender” (Fine, 1998, p. 152), it is essentialist, as I came to see, to assume that only a person who has experienced a disease can research it or understand the experience. In fact, it is just as essentialist as assuming that only a medical or academic “expert” can research a disease experience. It is essentialist to recognise another’s subjugation and not be able to see beyond that, so that the person’s entire identity becomes their romanticised subjugation (Buzard, 1999; Fine, 1998). It is very much worse, in my experience, to recognise one’s own subjugation and not be able to go beyond that identity. The story one attempts to tell in that case cannot be one’s own. Instead one begins to act a role, to play the part of the victim.

There is another side to the coin. Part of the function of autoethnography is to subvert power relationships. Couser describes ethnographic research experimenting with ways of achieving this and of acknowledging the Other without othering (2009, p. 89). This can be done by revealing such relationships or showing tensions or by giving the Other a voice. However, I can foresee that one’s own position as the “giver of voice” can become hegemonic. It is a powerful position to occupy. You decide who talks, how much and when (Allen & Hutchinson, 2009). This type of position can prevent dialogism. Self-scrutiny and clarity about one’s own biases are important in any research, but essential in autoethnography. An autoethnographer might veer between being the disenfranchised voice of the victim and being the overlord of the text. The story can simultaneously become one of victimology and oppression. One’s own power should be subverted or at least challenged, if one wants to present an accurate account of events.

Moreover, one method of inquiry does not negate others. I have used autoethnography; Crowley-Matoka’s (2005) study of the post-transplant experiences of Mexican kidney transplant recipients has used interpretive and political-economic approaches to ethnography. This does not invalidate her findings or mine. This was a mental leap that I have had to make. One’s essentialist conditioning runs deep. When I began my study, I began it in reaction to voices that I believed oppressed me and did not understand my experience (Richards, 2006). Soon I discovered that I did not myself fully understand my experience and that I had essentialised my identity as a transplanted person. I came to see, in the course of my research, that I was not inquiring into me versus “them”, but rather into how I situated myself and my own experiences. I began to feel trapped in the space from which I had begun to speak, a possibility Buzard (1999) warned about.

Just as researchers can be trapped in essentialising behaviour when they undertake research, they can also be trapped in essentialising behaviour when they read. Research, when it

considers itself and its methods, sometimes tends to forget that producing the research is only part of the process. In certain senses the research process includes how and where it is received, not only the action of “doing research”. Ethical behaviour is at stake here, both traditionally and in postmodern terms. How do we trust what we read, or do we read in a different way? New criteria suggest a different engagement with the text (Denzin, 2009; Richardson & St. Pierre, 2005). I have not explored the issue of criteria of reliability because that is a research topic on its own. Is authenticity a problem as a concept? How do we know when something is authentic? Can we count on ourselves to read ethically? I am not able to pursue this in my dissertation, but it needs further examination.

Autoethnography needs to be long in order to do its job. As Miller puts it (in Brody, 2003, p. 37), “[a]ll stories are potentially interminable”. You cannot summarise a story without its becoming a different type of story, one that has been chopped up and reassembled without some of its parts, one that has been interpreted. The length of a story is not dissimilar to the length of a piece of string. There are usually strict word limits on articles, dissertations and other types of academic writing. This may not be in the best interests of autoethnographic storytelling.

Connected to this is the idea that stories work holistically. Academic writing works linearly. Necessarily these types of writing are read in different ways. An autoethnographic reader needs to be aware of this, as much as an interviewer needs to be aware of the interviewee’s words, nuances and complexities. An autoethnographic reader might need to be more involved in (re)constructing the text than an academic reader usually would be. An autoethnographic reader needs to read recursively too. This does not always suit modern life. My poster about the experience of dialysis ended with this sentence: “This poster is now part of my story too...” (Richards, 2009b).

Each time I wrote a journal entry (Richards, 2007), wrote an article (Richards, 2008), read a paper (Richards, 2009a), created a poster (Richards, 2009b), or edited a draft of my dissertation, I found my story had escaped from me again and changed shape. At first I resisted this and tried to tie the creature down, but then I found it was more fun to let it do what it wanted to do. Each time a text is read, it will be different, whether it is being re-read or read by a new reader, even as it is being written, rewritten or told by someone new. This and the blurring of definitions can be seen as a crisis of meaning (Denzin & Lincoln, 2005) or perhaps it is a new constellation of meanings.

### 3.6.2 *Challenges of blurred categories*

The issue of blurred categories has been the subject of much academic debate. One of the blurred categories is that of blurring genres of writing (Denzin, 2009). Genres become “mixed” as a response to the changeability of the world and our response to it (Glissant, 2002). Blurring them allows us to reinvent them, as bricoleurs, better to suit our purposes. Criticisms of blurring genres include Marcus’s (1998) concern that this leads to experimental writing that does not go further than being an experiment and can be self-indulgent. Blurred genres can also perturb readers because they defy categorisation (Brettell, 1997; Geertz, 1973). Does this help or hinder our understanding of what they are doing? Does it force us to take a closer look at what they are doing, instead of accepting certain givens? I am inclined to think so. The traditional forms of academic writing can too easily be seen as natural and be read uncritically, so that the power structures that these forms reinforce (such as positivism, post-positivism, or empirical research) are re-entrenched. They are for this reason highly unsuitable for postmodern qualitative research. The form of your writing structures the form of your knowledge.

By blending cultures, epistemologies or ontologies, autoethnography allows the writer to tell a unique story that represents ideas about a particular part of society and allows meaning to be derived from this, by involving the writer as a character, whether it is as a central character who narrates or as a peripheral observer who is nonetheless involved in what unfolds (Dwyer & Buckle, 2009). Autoethnography, in other words, can take many forms along a continuum that ranges from autobiography to ethnography. However, autoethnographies are inclined to have a particular quality: Jones (2005) explains that autoethnographic texts tend to resist categorisation and closure because of their liminal nature. She describes autoethnography as being “between story and context, writer and reader, crisis and denouement” (Jones, 2005, p. 764) and as a type of writing it points to “the power of the in-between”, of “occupying a space between theory and practice, analysis and action” (Jones, 2005, p. 784). This type of writing deliberately reveals tensions and raises questions. This can be disconcerting if one is inclined to want closure, and a researcher might forget that closure is not the goal of this type of research.

For my purposes, understanding that the autoethnographer is a “boundary-crosser”, whose role can be characterised as having a “dual identity” (Reed-Danahay, 1997, p. 3), allows me to use my private identity as a patient to challenge and question some notions of power, legitimation and legislation. On a most basic level, the autoethnographer is both the subject and the object – both the insider and outsider. As autoethnographer, I can introduce another voice than those of medical doctors and sociologists into the research on the subject of organ

transplantation. I can speak back to power from a unique perspective (Pratt, 1992). Reed-Danahay (1997), however, warns that constructing dual identity in a binary way is too simplistic for an understanding of processes of representation and power. For Reed-Danahay, the teller is one who is not completely “at home” in either world, rather than one who belongs to a colonised world (1997, p. 4). This allows the teller to transcend everyday conceptions of self and social and, to some extent, to rewrite them. At the core of any autoethnographic study are issues of identity and selfhood (Reed-Danahay, 1997). This is what I came to see in my own autoethnographic journey.

In-between lives, such as those of people who are in one or other type of remission or who have had organ transplants, are particularly well suited to this type of writing, because they play themselves out in two often contradictory worlds – the world of the well and the world of the ill. The person in remission does not fully belong in either. Furthermore, the tension between being subject and object can serve to highlight aspects of a social situation and to capture aspects of embodied experience. This can subvert power structures that are often not questioned in other types of discourse. In addition to this – and for the purposes of my work, this is essential – wherever you are, a trace of where you have been remains, like a Derridean palimpsest (Derrida, 1998). The trace does not go away and cannot be ignored. Its presence allows “the conception of what cannot be said” (Glissant, 2002, p. 293). This is necessary in forming new identities, leaving old ones, or dealing with unspeakable things. This is why it works especially well with illness narratives.

Another type of blurring occurs in the research I read and in my own work. I found this blurring particularly problematic: the blurring between liminality as ritual (Turner, 1969; Van Gennep, 1960) and liminality as state (Crowley-Matoka, 2005; Little et al., 1998). Perhaps it has allowed me to interrogate more thoroughly what liminality, ritual and condition might mean for illness narratives. It did, however, cause a tension so severe in my work that it almost brought it to a halt. Other troublesome tensions I experienced while writing were the tension between knowing and unknowing, and the desire to find closure while resisting it. Making versus analysing is a tension in any type of writing, academic or otherwise, but it can derail one methodologically in autoethnography. These tensions tended to paralyse me instead of allowing the dynamic interplay of ideas. This could have been partly tensions in my personality between a desire for order and a love of chaos. I was at any rate compelled to re-examine these tensions constantly, so I gained deeper understanding of the epistemological and ontological issues of my research.

Liminality is a part of the postmodern experience and a part of illness, especially chronic illness. It is a state created by people to help understand changes in identity (Turner, 1969;

Van Gennep, 1960). In recent studies of chronic conditions, liminality has come to be seen as a state of being that people struggle to understand (Little et al., 1998). This bewilderment can be seen in biographical work too (Richards, 2010). In ritual liminality (Turner, 1969; Van Gennep, 1960) a person withdraws from society in order to put aside their old identity and take on a new one. A ritual action is needed to bring the person back to “the land of the living” and recognition of their new identity must be made by both the liminal person and the society to which they return. This implies that the new identity needs to be understood (and made fixed) through ritual.

Recent studies of chronic illness (Crowley-Matoka, 2005; Little et al., 1998) have used Turner’s (1969) and Van Gennep’s (1960) idea of liminality, but have forgotten that it was meant to be a ritual state, one that is purposefully created, not a state that occurs as a result of physical changes, where one has no control over its duration. Seen this way, liminality can be an obstruction to getting on with one’s life or something to overcome, a condition associated with illness and being Other. When illness is chronic, that condition can become life-long and people struggle to come to grips with a situation they feel should not exist. It becomes a type of limbo instead of a powerful way of coping with changes in identity and moving between structure and anti-structure. But what if that is what life is? What if we are always ceasing to be something while becoming something else, even if we are not coping with the effects of chronic illness? It is all too easy to revert to traditional categories of understanding and to attempt to resolve this third state into being health or illness, and then feeling disquieted when it fits neither, because it is something else.

As I developed my ideas and my narrative, I was forced to re-examine periodically the blurry issue of liminality. This caused me to begin to argue that what we see as liminality in chronic illness is not in fact liminality, but that the changeable nature of the experience of chronic illness itself. This changeability and in-betweenness is intrinsic to chronic illness and the identity of a person experiencing chronic illness. This needs closer examination in autoethnographic writing, which often seems to be trying to resolve that blurriness. Sandelowski (1991) describes stories as liminal and part of the hermeneutic cycle of reinterpretation. I find it better to call them dynamic and littoral. Part of this dynamic nature comes from the irresolvable tension between the blurred aspects of their identity. Just as I blend two cultures in being both ill and well, displaced and (in some senses) replaced, researcher and researchee, writing about illness holds immense scope to blur and blend genres and, perhaps, to form a new identity.

Autoethnography poses some interesting questions about representation, especially in terms of subject/object dualism and mind/body dualism. In autoethnographic writing one can be both

the subject and the object of a narrative. One can choose one's identity to an extent. What does it mean to be both subject and object? If one accepts one is both subject and object, is one not still subscribing to Cartesian dualism? Writing about embodiment and emotions may not allow embodiment or feelings to express themselves, but simply become another way of representing them and objectifying them. Can this situation be escaped from through writing about embodiment, or does this reveal that as autoethnographers, and indeed as representers and representees, our responsibility is to continue to question our position(s) and to avoid settling into complacency? If one can achieve this, as I hope to in this dissertation, one's subject/object positioning and mind/body relationship will remain dynamic, fluid and individual.

### **3.7 My approach**

#### *3.7.1 What I am doing*

My approach differs from Chang's (2008) cultural-analytic approach in the sense that I am not conducting a cultural study of a population group as an anthropologist or sociologist would. My study is in and of narrative. My intellectual culture is one of narrative. My academic background is in literature and ancient history, both of which I could only access through written texts. Frank draws a distinction between thinking *about* stories and thinking *with* stories (Frank, 1995). My hermeneutic approach causes me to suspect that one always does both. The telling of a story is a type of littoral zone which one must needs traverse many times. It is a zone that shifts and changes constantly.

Narratives are themselves cultural constructs. However, they are more than that. Narratives are data only to an extent and they can be analysed only to an extent. My narratives speak to each other and to narratives beyond themselves. They are formed and informed by other narratives. They are always themselves and other. I am not concerned so much with diverse cultural backgrounds as I am with unpacking my own. For the purposes of this study I need to be able to understand my own perceptions against the cultural backdrop whence I emerge.

Ontology has its uses: it pays to know people's contexts. Chang (2008), for instance, is a sociologist. I am a narratologist. My emphasis is on the graphy side. How and why we write as we do is as important as what we say. In fact, it is what we say. We seem to understand how the self and the culture affect how and what one writes, but the graphy part affects the auto and ethno parts too. If you do not have the linguistic means or the patience to work at it, and if you do not realise there is a process with writing that is as important as what you are trying to say, you will not be able to say what you mean (Elbow, 1973; Hjortshoj, 2001).

My academic training in English literature taught me to do close, detailed analyses of texts, so my writing tends to be peppered with direct quotes from documents I have read. This will likely cause my work to have a different flavour to that of people trained in the social sciences, who generally go more for a theoretical and conceptual reading of texts, extrapolating the main ideas (Goodall, 2008). My way of reading and writing shows different things than other approaches that are more grounded in the social sciences. In my understanding of texts, the details are what make the whole. The choice of word is significant. It makes the meaning. The danger of extrapolating is that you must *perforce* paraphrase and interpret what others are saying, despite your coming from a different context and position of power. On the other hand, if you quote what they say out of the context of the whole narration, it will not mean exactly what it did before either. This applies to segments of narrative and to narratives of length. If you change the words, you lose the identity of the person talking and, in doing that, you colonise them and take over their textual being.

This more “graphy”-centric autoethnography will allow me to provide a thick and textured description of a state of being and also to interrogate assumptions about that state of being (Ellis & Bochner, 2000; Ettore, 2005; Muncey, 2005). Autoethnographic narratives do more than relate the history of a life (autobiography). They allow an ethnographic understanding of that life within a certain context and acknowledge the researcher as influenced by and influencing her environment as her identity changes. Just as ethnographers previously sought to understand other cultures than their own and returned, knowing more about themselves (Geertz, 1973; Malinowski, 1922/1984), so can one seek to understand oneself and discover more about others. There are different ways of doing this (Chang, 2008; Ellis & Bochner, 2000; Ettore, 2005; Richards, 2008; Wall, 2006). I have chosen a narrative approach that is hermeneutic, because it is reflexive and discursive and allows me to dialogue with other texts. The phenomenological, experiential nature of the text allows me a deeper understanding of my own perceptions and identity.

Along with the usual academic audience for a dissertation, autoethnographic research may in future allow my study to reach health care professionals (doctors, nurses, counsellors) and lay people (patients, families of patients, carers, and friends). A narrative approach with a strong theoretical and ethical grounding might allow the professional care providers access to the lived experience of organ failure, transplantation and life afterwards and a person’s self-perception through this, rather than just to the data and symptoms (Richards, 2008). In addition it might allow people from the broader chronic illness community to see some of their experiences reflected, particularly as there are few renal narratives and virtually nothing about long-term experiences of kidney transplantation (Nicholas et al., 2011; Richards, 2008).



I am speaking back to power, but not only medical authorities, the power I initially wanted for myself that can silence other voices and other narratives as effectively as medical discourse. I have had to speak back constantly to my own inner empiricist demons that urge me to treat narrative as a way of recording things, to forget the aims of qualitative research, to buy into the idea of the omniscient, powerful researcher, and all that these temptations imply. In my own document I have had to resist the urge to conform to an often dominant ideology of research. Ironically this troublesome ideology closely mirrors that of quantitative research, from which it is allegedly trying to escape (Chamberlain, 2000; Denzin, 2009). One of the first ways in which I was constantly reminded of my urge to conform was when I realised in early versions of writing my story that I tended to keep to the medical tale. Subsequently I came to see that I wanted to be the Romantic hero on a utopian quest. Later I realized I was not yet out of the woods, because I found myself evaluating my own work with criteria I had imported from other types of research (Do I have enough facts? Have I substantiated this? Is the narrative coherent and unified?). Old habits die hard.

One of the first questions I asked myself when writing this chapter was: Why is telling my story a way of writing back to medical and other authorities who had made decisions about my life for so long? To whom am I writing back? Ironically the impetus for pursuing this study was indeed a way of writing back to authorities I felt had denied me my humanity and dignity as a transplantee (Richards, 2006). However, once I began my study, I realised that I was not writing back so much as writing backwards. I was not writing to an imagined panel of faceless institutional lackeys, but rather to myself now, to an earlier version of myself and about an earlier version of myself. I was also in a sense writing forward about myself now towards what I might become and in so doing I was beginning to make my story anew.

As my story progressed, I found I was no longer speaking from the place in which I began to speak, because I was no longer there. I had moved. Because of the recursive, iterative nature of story-making, I would not necessarily call this movement a progression, certainly not in the linear sense. But it was a change. This change might not be easy to see in the version(s) of the story in the chapters that follow. After all traditionally a story has a beginning, a middle and end. It is constructed in such a way that it has direction and development. Instead the change is seen in the fertile, liminal spaces between the versions of the story and in the juxtaposition between the versions and the documents of which the story consists, including drafts of the dissertation, two articles, a conference paper, a poster and a research journal (Richards, 2006, 2007, 2008, 2009a, 2009b, 2010). Personal writing can be seen as a progression from uncertainty of one sort to certainty, and then to uncertainty of a different sort. The further I got



from the big event of my transplant and the longer I had to deal with post-transplant uncertainty and lack of closure, the more these became part of my everyday life and identity.

### 3.7.2 *Why I am doing it*

I am writing this dissertation because I expect by so doing that something will change. What that something is I am not sure. Paradoxically I am also writing this dissertation so that something can stay the same, so that I can fix it permanently in writing and it can be remembered. Again I am not sure what that something is. It could well be the same thing that I expect to change.

I am focusing on writing to the extent that I have, because I am arguing for a broader definition of autoethnography than Chang's (2008) or even Ellis and Bochner's (2000). I believe more attention needs to be paid to the act of writing in autoethnography. This has been touched on, but not elucidated (Jones, 2005; Reed-Danahay, 1997; Wall, 2006). My dissertation is an attempt to take this somewhat further. Autoethnography is an interdisciplinary method and should not be restricted methodologically to one or other discipline. If one uses it within a discipline, it can be adapted to the discipline's requirements, but can also be displaced (Shildrick, 2002), set free from its predetermined framework, so that its meanings are less limited. This can allow it to be interpreted differently through a type of defamiliarisation.

There may be no autobiography *per se*, because the self is always political and always constructed. Chang (2008) finds it ironic that self-narrative involves others. Why? Narrative is a social act. Each self is part of a greater whole and achieves his/her identity in part through interacting with others. It's a question of focus. Because autoethnography is analytical and interpretive (Chang, 2008) as well as aesthetic and creative, researchers can find it difficult to pay due attention to everything.

When I reflected on the ways in which some autoethnographers had used artefacts such as photographs, for instance, I had some concerns. I was perturbed by Muncey's (2005) use of photography in her article about teenage pregnancy and identity. She has selected photographs to use as symbols and discussion points of her journey as an autoethnographer and as a person who experienced teenage pregnancy. She discusses some of the theories around photographs, but she does not discuss what taking a picture involves. The photographer chooses what to put in it, frames the subject in a certain way, arranges the parts, chooses the light, pushes some items to the background and leaves others in the foreground. In Muncey's case, other people took the photographs of her, so they have constructed her. She accepts what they have seen. She does not discuss this. I feel ambivalent about how she has used these pictures, but cannot deny that it is useful, as she uses the images to construct

a stronger self-image that ties in with society's expectations. Her narrative is a story of the recovery of self-esteem, but this tenuous self-esteem seems very much dependent on her public identity. Her relationship with her daughter (and indeed the rest of her family) seems not to be part of her journey. Does this article flounder because Muncey tries to cover too much? I had to wonder if my own endeavour might not experience the same type of problem, as I too was looking at life-long experience, instead of a short-term event.

Although Cook (1996) does not name her methodology autoethnography, she is creating an autoethnography through medical artefacts (forms and x-rays) to express her medicalised identity in a composite way. The composite nature of her article is strengthened by the focus being on a part of her life instead of her whole life. Like Muncey, she is concerned with the power relations of representation. She uses her article to demonstrate her experience of being anatomised and compartmentalised by her medical practitioners, and illustrates this by using their artefacts to do so. In doing this she deconstructs their images of her and replaces them with her own. This is autoethnographic in Pratt's (1992) sense, because she speaks back to power. She also shows how the medical discourse insidiously alters her own self-perception. It is possible that I warm more to Cook's article because it is about the experience of illness, with which I am familiar, instead of teenage motherhood, with which I am not. Also, Cook uses theorists with whom I am familiar, Foucault and Barthes, while Muncey uses theorists with whom I am not familiar, Kuhn and King.

These two articles showed me that artefacts give concreteness to an autoethnographic work and prevent it from being too abstract. So I decided to base my own work on my own artefacts of various types. Autoethnographic narratives do more than relate the history of a life (autobiography). They allow an ethnographic understanding of that life within a certain context and acknowledge the researcher as influenced by and influencing her environment. Artefacts can achieve this by showing complex instances of key points in one's life. But I had no photographs and few medical records in my own possession. As a patient in a state hospital I was seldom granted access to my own files and was never allowed to keep anything. It seemed my medical data belonged to others, not me. The only artefacts were ones I had created over the years and they were all in narrative form.

Writing is an artefact. I do not have the ethnographic artefacts that Muncey (2005) has. My texts are simultaneously more literal and more abstract. Not photographs, epaulettes and official documents, mine are journal entries, memories and dreams. All of my texts are liminal texts, the products of liminal or littoral states recalled. And so my study takes the form of a narrative, or rather of a number of smaller narratives juxtaposed to each other and compiled into somewhat larger ones of different shapes. These narratives form a dialectic with the

academic parts of the text. The object of this is to destabilise my text as a whole and to act as a reminder that no story, academic or personal, is ever complete and that any “truth” is contingent. Through writing my story I attempt to capture it, to fix it, to remember it. Paradoxically I also try to set it free to live and grow. I try to create my story and to give some type of form to my experience, so that it can truly be an experience and be mine.

To some extent the chapters will build on one another and develop themes that are common to all. Sometimes, however, chapters or parts of chapters will break down, contradict or deconstruct (Derrida, 1998; Selden, 1985) other chapters or parts of chapters. Living with a life-long chronic condition is a complex experience of many layers, or, to use another metaphor, it is seen through a fractured lens. It is postmodern in that the way it is written will become its epistemology. Not only will there be possible contradictions and erasures, but there will also be other disjunctions. These might take the form of silences, absences, mute presences, gaps (sometimes of several years), or stories that may seem different or unrelated to others. An album of snapshots creates a bigger picture when seen as a whole. Likewise a collection of smaller narratives is greater than any of its constituent parts. The whole is, however, still not complete. No photograph contains every truth about its subject; instead it is a framed, symbolic representation of a moment in time (Muncey, 2005). Likewise narrative smoothing (Spence, 1986) can achieve the same in a narrative that framing does in a photograph.

Finally, writing is a technology in the sense that Leder (1990) describes, in that it allows one to extend oneself, one’s vision and one’s experience. It creates a symbolic skin similar to that of one’s house, one’s clothing or one’s national identity (Helman, 2007). This “skin” is permeable and can be incorporated by a reader, creating in some small way, perhaps a temporary consanguinity between reader and writer. My hope is that my research will be a type of ethical and compassionate conversation with the reader that may lead to further research or in some way change the reader and the reader’s views of my subject as I and my views have been changed.

### **3.8 Research ethics**

A discussion of the ethics of autoethnography is unavoidable by virtue of its blurred nature. Followers of a more traditional way of research would question the ethics of a research method of which the researcher is part. Postmodern researchers would maintain that researchers are always part of their research and that it is unethical to insist otherwise. Instead of thinking of ethics that uses narrative versus ethics that does not, it might be more useful to think of ethics in which narrative is implicit or explicit (Brody, 2003).

Narrative knowing is different from other ways of knowing, because narrative rationality differs from propositional rationality (Goodall, 2008). Narrative lets you know “what it is like”, instead of “knowing how” or “knowing that” (Worth, in Goodall, 2008). Narrative knowing allows a type of coherence to emerge that has far-reaching implications:

Among those for whom the story is alive there is a revival of ethical authority otherwise almost effaced in our society. For it establishes on a new basis the coherency of social and personal time. It makes it possible to recover a living past, to believe again in the future, to perform acts that have significance for the person who acts. By so doing it restores a human form of experience. (Crites, 1971, p. 311)

This in turn allows both reader and writer to take a more ethical stance towards life. As the story unfolds, it surprises the writer as it tells itself. Narrative research contravenes any idea of authorial omniscience. Even though the story is your story, it is not truly yours until you have told it. You cannot know a story until you have told it; hence every story is a quest story in some way. To conceal that quest is to defeat the purposes of narrative methodology.

Narrative style does no more simply depict a scene than a photograph “simply” depicts a scene. While writing about one’s own experiences can be seen to raise ethical problems, it can also be seen to help “develop ethical selves engaged in social action and social reform” (Richardson & St. Pierre, 2005, p. 959). Richardson and St. Pierre (2005, p. 959) argue that writing is “a method of knowing”, where the author’s position as knower and teller will always be examined in one way or the other. In a previous article I described qualitative writing as a negotiated text, not “a neutral tool, but a complex interplay of cultural factors” (Richards, 2008, p. 1720)

Any form of representation, even representation of oneself, must be linked to what Csordas calls “being in this world” (1997, p. 277) and the ethical implications of this. Precisely how one might be in this world can be discussed in terms of various types of dualism. The difficulty of any dualism is that one of the pairings is always viewed as superior (day/night, male/female, black/white, subject/object). If one fights for the underdog of the pairing, one simply reverses the dualism and the split remains. Seeing the pairing as “equal, but different” is often a form of intellectual dishonesty; equal things are the same, not different. Collapsing the dualism seems to work only in the short term. Dualisms are not fixed but dynamic, the result of power structures that are changeable. If they are viewed as dynamic and maybe even complementary, they can be useful in advancing one’s understanding.

The type of dynamic dualism that one experiences when writing about oneself as one oscillates between subject and object allows for self-reflexivity and an interrogation of one’s

ethical stance. “The politics and poetics of representation” (Reed-Danahay, 1997, p. 3) go part of the way towards describing the processes and experiences. Regarding illness narratives, selves are created through writing and an ill self is in a state of perpetual alterity with the “normal” world (Frank, 2000, p. 136). The recognition of this is an important ethical act in a world where so much can be quantified. Speaking as a member of a marginalised group is an emancipatory and ethical act whose implications extend beyond oneself.

### **3.9 Where this led me**

My philosophical considerations were weighty, not to say burdensome. It was with gloomy and apprehensive thoughts that I began to revise my chapters, because, contrary to more conventional ways of writing up one’s research, I had already written them after some initial forays into the uses of autoethnography. I reasoned that now that I had written the chapters, analysing them with an eye to my recently acquired philosophical qualms might allow me to deconstruct them or, I desperately hoped, to synthesise the main ideas in them (but not, I assured myself, in a way that would dismay Glissant or be utopian or Romantic). I wrote a big “NB” in my notes, next to “I am exploring something here, not setting out to prove something”. This lends a different flavour to my study, because I am not setting out with the end already in mind.

Despite what I had understood in Glissant’s work, I was fairly certain I would need to examine ontological and epistemological issues in my next phase. And so I did, reassuring myself that I didn’t need to answer all the questions. I reasoned my postmodern, hermeneutic, iterative process is itself a type of methodological rigour: revisiting, interpreting, questioning, backtracking, to try to see what the story is (at this point). Does it consider reflexively the relationship between researcher and subject? Constantly. Can my theory emerge from the practice and experience of writing my research? I hope so. Can the experience of writing become part of the experience of living and part of the methodology (or method) of research? Can practice precede theory? Denzin and Lincoln (2005) and Kleinman (1988) seem to think so.

Equipped with a cache of reading and a glimmering of understanding about phenomenology and existentialism, I decided to return to writing my dissertation chapters. Of course I had started with writing them before starting this chapter, because my story was what I knew (I thought). I had started with the chapter about dialysis. The events around that period in my life told me it was a tipping point for me where matters could have gone one way or the other. I had already encountered some surprises in writing it. I now knew that I would have to return to my dialysis chapter again and retell to myself what I had learned and unlearned while writing

the stories, but for now I could feel a sort of temporary break from the liminality of unknowing. Perhaps I was doing autoethnography at last! This reminded me very much of Ellis's (2004) reminder that autoethnography is not linear. Being in the experience and being able to move out of it emotionally are essential for autoethnographic understanding. This discovery felt like the frail but trustworthy link that Glissant (2002) refers to between the wild diversity of the world and the balance and knowledge I desired.

I was initially excited by Zuss's (1995) treatment of *métissage* as strategy – not only a way of representing something, but a way of interacting with it. As a postmodern document, the autoethnographic text functions in a metatextual way as well as textual way: its form mirrors its content. It performs its own uncertainty. It makes explicit its author's philosophical antecedents and journey to understanding. It is not only a cunning plan to challenge power structures. *Métissage* is a strategy for dealing with becoming, with metamorphosis, with "new forms of subjectivity" (Zuss, 1995, p. 176). In illness narratives it can also be a strategy for dealing with unbecoming – with ceasing to be and with things that are unspeakable. It might even help counteract disappearance by creating other possibilities than the "norm".

However, my elation about my miraculous closure was of course short-lived. Stories only serve their function in the living and the telling. Only then can they truly "educate the self and others, including the young and those such as researchers who are new to their communities" (Clandinin & Connolly, 2000, p. xxvi). What does it mean to tell the story of yourself? Can you remain unchanged if you do that? Do you fix your identity in telling it or do you unfix it? And once you've told the story and are changed by it, does it still belong to you if you are not who you once were? Do you need a new story now? Is a story a type of transitional object or part of a ritual of reintegration to end a liminal state? This is what I meant to find out. And, in the manner of all stories, to find the end, I had to start at the beginning (again).

Part of the reason for my recursive practice at this point was that I had some lingering concerns. The first is a personal one, perhaps related to vanity. If I am both researcher and researchee, but am still myself, then perhaps I need a new title, having undergone a type of academic Creolisation. I fear, however, that such a change may rob me of what authority I have, since, although I shall cease being a researchee, I shall no longer be a researcher. I do still cling to traditional forms of validation. If I am both, does this change the constitutive relationship between researcher and researchee or does it merely reify it? Perhaps I would, instead, oscillate between being researcher and researchee, in a constant state of becoming and ceasing to be. "But," says Glissant, "can one endure a perpetual becoming? Do we not need the reassurance of anchoring our identity in a territory, a law, a founding myth?" (2002, p. 292). We shall see.

My second concern is that if I am indeed writing an autoethnographic text, I want to be sure my “entire” text is, in fact, autoethnographic, even this very chapter. As I contemplate it, I wonder fretfully, “Is it autoethnography yet?” I am perturbed that I have no way of knowing.

My third concern is one seldom referred to by autoethnographers: What if I can’t write well enough? Average writing skills are not necessarily an impediment in many areas of academic research, but will be one here. The other side of the coin exposes an ethical dilemma: If I can write well enough, that presupposes ethical impediments – a disingenuous view of writing and texts, a certain craftiness in composing them, an ability to mend invisibly or to cover my devious tracks. Then I discovered that *metis* has another meaning than a person of Creole descent (Glissant, 2002). This meaning is older and derives from classical mythology: cunning intelligence or craftiness (Beard, 2002). This seemed strangely significant to me as I embarked on retelling my story.

Until I began working on this research my story had been strongly medical and had concerned itself with facts and figures. I decided this was a good enough place to start (again). But this time, instead of starting with creatinine levels or blood pressure, I decided to start with a number that was very much more significant to me: 548820.



## **CHAPTER 4: END STAGE RENAL DISEASE OR THE BIRTH OF 548820 - “PROTRACTED LIMINALITY” AND THE SUGGESTION OF A THIRD SPACE**

### **4.1 Introduction**

Who is 548820? Why, me, of course. That was the number I was given when I became a patient in the adult renal unit of the Johannesburg General Hospital. However, this chapter concerns my childhood and adolescence growing up with kidney disease. I was not 548820 yet, but then again I was not really anyone yet. Looking back on it now, I find it inevitable that I should have become a number in a system, even though I never knew my childhood number. My mother and my doctor kept it from me. Because so much of my early narrative was medical, overtly, explicitly and only medical, I was a number waiting to happen. Numbers of different sorts have dominated my life since earliest memory: creatinine, urea, blood pressure, red cell count, white cell count, age, height, weight.

I did not start writing my dissertation with this chapter, but instead with the chapter that follows chronologically, the chapter on dialysis. Nonetheless, this chapter remains the most preliminary of all, because when I experienced the events I describe I was myself so preliminary, only a child, in a world of other people's stories. Its form reflects my desire to tell the story or stories of that time – it is largely personal narrative and little of it is conventionally academic. I have attempted to include some theoretical, thematic and methodological concerns, but as hard as I try to include them, my eager story pushes them to the peripheries of the text. This chapter performs something of the messiness of life itself through the associations and varying amounts of time spent on different sections. In this it is postmodern. The personal narrative dominates and the academic interpretation itself is reluctant to be contained. It emerges from time to time in my personal narrative, although I have tried to keep the two narrative types separate.

This part of my narrative really has never been told before and that saddens me. I was a precocious child, reading at three and with an abnormally large vocabulary, a “walking dictionary” as a classmate's mother, who was also our history teacher in high school, called me. But I did not have the words to articulate my story and I had no point of reference. Unlike many who tell the stories of their illnesses (Bauby, 1997; Broyard, 1993; Cojocaru, 2007; Ettorre, 2005; Frank, 1995; Grealy, 1994; Hornbacher, 1999; Klug & Jackson, 2004; Kolker,



1996; Linton, 2007; Oakley, 2007; Sparkes, 1996, Tillman-Healey, 1992, Thomas-MacLean, 2004), I had no memory of ever being or experiencing anything else.

Not only that, but I grew up with the condition, but without peers. My paediatric renal specialist arranged his clinics so that his little patients never had to wait to see him. He believed that children should not be in hospital any longer than necessary and he tried to make our lives as much like those of our healthy peers as possible. This meant we never met other child patients unless we were hospitalised and I never was as a child. I had no other child narratives against which to compare the fragile beginnings of my own. So I scoured the literature for children's stories of renal failure. I came up empty-handed (Richards, 2008). I discovered that others have had as little success in unearthing children's renal narratives (Darbyshire et al., 2006; Nicholas, Picone & Selkirk, 2011).

In piecing together my ancient narrative, I resorted to bricolage by using what was available to me to carry out the study (Denzin & Lincoln, 2005; Kincheloe, 2001). How to tell it was a problem. There was so much to say and yet so little on which to peg it. Because I was writing about experiences that occurred long ago and over a lengthy period, I found I did not have specific events or conversations on which to base my narrative, although one or two came back to me after some writing. Instead the narrative was a type of blurring together of many repeated events (all those clinic visits, the endless food restrictions and, of course, the blood-taking). I suspect my story gushed out of me so strongly from relief at finally being able to tell it. This left me with a feeling of being overwhelmed. This could have been due to the sheer quantity of what I found myself writing, or it could have been an accurate recollection of how I felt about my situation as a child. I realise now how helpless and how passive I was in the face of overwhelming illness and overwhelming medical care in which I had no say. I think I knew it. By the time I was in my early twenties my dreams show this clearly.

The first part of my story in the chronological sense is difficult to situate in a postmodern narrative, when it is almost pre-historic. It is very easy to fall back into the traditional view that story-telling is an act of memory alone. It is particularly easy when the events you are writing about happened long ago and you are cudgelling your brains to remember them. Who you were then is not quite who you are now and, at the same time, it is. It is as if your narrative self – both the self you are constructing in the narrative and yourself as narrator – are a “third” version of you. These entities are not you present or past, but a blurring of the two and, at the same time, someone else.

Moreover, each narrative is the intersection of many other narratives. A snippet of a childhood composition about favourite things occurs at a moment when one is also afraid of needles,

being hit by one's sibling, escaping a horrid ballet class and not being allowed the favourite foods one so craves with every skinny fibre of one's 9-year-old body. Are these subtexts in one's official narrative about the sunny side of life? Yes and no. I can see the gaps, fissures and omissions in my own narrative, but I doubt any other reader could.

#### **4.2 Why I decided to use artefacts and how I found them**

Muncey (2005), in her autoethnographic description of her teenage mother status and growth into a new identity, chose to use certain artefacts from her past to explain her experience and to deconstruct it so that she could make a new identity. It was not always clear whether she saw that story-telling was also story-making and not only an act of memory. My impression was that she was writing back, trying to create a type of counter-narrative (Nelson, 2001) to society's master narrative concerning teenage mothers and that this narrative was an exercise in recovering a lost voice. Her approach to autoethnography was in the tradition of Pratt (1992), writing back to power. In doing this and in using the artefacts at her disposal (photographs, epaulettes, a childhood book), she deconstructs the master narrative ironically through using narratives that others have made of her life. She does not remain in the place she started from, disempowered and voiceless, and so evades the fate of becoming entrenched in a narrative position of victimhood that Buzard (1999) warns against.

Reading Muncey's article inspired me to do something similar. Those early years of kidney disease occurred when I was so very young that I had no narrative of my own. Instead I was surrounded by and infused with others' narratives of me and my medical situation. Of course the dominant narrative, following the crisis of HUS, was medical. This narrative necessity was compounded by my family being medical too. My mother was a nursing sister, my father a medical doctor. They tended to see things in medical terms. Some of the doctors who treated me were also their friends and colleagues. So mine was a very medical story. I should say instead that the story about me was a medical one, because the story was not mine, but other people's.

I would tell it too, when required. I knew it by heart. There were two versions. The first concerned the actual events of my medical crisis. I developed fevers and seizures at 8 months. I was rushed to hospital. No one knew what was wrong with me until I started haemolysing – meshes of platelets formed in my blood vessels and shredded my red blood cells. I bled internally, on the brain, in my organs. My body could not take the strain and I burst a hole in my heart, my liver shut down and my kidneys ceased working for 12 days. Blood transfusions saved me and, because I was so young, I was resilient enough to heal. The hole in my heart closed, my liver and kidneys began to work again. But my kidneys had been

scarred. This affected my blood pressure, which in turn scarred them more. It was a vicious cycle. Although I was treated for high blood pressure, the damage was irreversible. Diet and medication could only slow down the inevitable: I was going to go into kidney failure. It was only a matter of when.

The second version of the story was my mother's. It concerned all the medical details described above, but it included her role in saving my life. It was she who had rushed me to hospital when others dismissed my illness as a childhood fever; it was she who had diagnosed my condition and it was she who had hidden the half-used bottle of blood from my first transfusion, in case I should need another. When I haemolysed a second time, she whipped the blood out of the back of the ward fridge and presented it to my doctors immediately. If they had had to wait for the blood to come from the blood bank, I would have died.

These narratives developed and replicated themselves as I grew up. Essentially they were always the same. The medical narrative explained my condition in terms of my blood pressure and creatinine levels, while my mother's narrative explained my health as a result of her vigilance and knowledge of what my readings meant. This showed that she was a good mother and a good nurse. Both my mother and my doctor predicted my future based on their narratives of my present. Here is where they diverged from each other. My doctor saw kidney failure as inevitable and spoke of transplantation. My mother saw my health continuing and transplantation as a vague eventuality when I was much older and if I had experienced future unfortunate events.

However, something was missing. By the time I was in kidney failure, in my late teens, I still had no narrative of my own and this was beginning to worry me, although I could not articulate why. Both the narratives with which I had grown up seemed incomplete to me, but when I tried to tell the story myself, I could not find a way of adding to what I had been told. After all, the story of a medical condition would have to be medical, wouldn't it? It took me many years to realise that I had been so affected by the medical narrative of my condition that I had not seen that I was not a medical condition myself. The stories were not about me at all. The medical one was about the progression of a disease and its effects on internal organs. My mother's one was about her struggles as a parent to help her child survive a medical condition. I barely featured in them. I came to see that even when I told the stories I was an unconscious baby in some and the passive recipient of others' care and decisions in others. This was at odds with my lived experience of the disease and its treatments. In short, what did it mean to me (Garro & Mattingly, 2000)?

I did not know what to make of it all. I suppose the narrative, had it existed, would have been, in some senses, a chaos narrative (Frank, 1995). But I could not tell the story and so it could not become a narrative. After transplant I tried for about six months, but could not get beyond explaining what my blood results meant and describing my prognosis. Others were eager to help by telling their versions of the new phase of the story and soon I began to notice a difference between their perceptions and mine. I gave up on telling the story of my descent into kidney failure. I decided it belonged in the past. I had a working kidney and a future. I chose to focus on that. I seldom referred to my medical condition any longer. I made sure I could pass as “normal” and considered it a success when people I encountered saw me as such. After five to ten years I grew used to my condition. I didn’t even see a renal specialist for a decade. I was like “everybody else”. Then, 16 years after transplant, it all came undone with my brush with the insurance company, and when I started my doctoral research, all I could write about was the endless renal diets, needles and pills that punctuated (and punctured) my childhood.

So I decided to reclaim my story, to write a story that was truly mine, and Muncey’s (2005) way of using artefacts seemed a good place to start. All I needed was a few artefacts of the experience and soon my own story would emerge, deconstructing the narratives that had defined my life for so long. Photographs, medical paraphernalia, pill bottles – how difficult could it be? I found that I had kept nothing of those years. I had not been hospitalised until my late teens, when my kidneys were failing. I had no photographs of key moments, because there were no key moments. Kidney failure is a slow, subtle and painless descent. I had no crises as I slid into it. It was only five years after transplant (when I was 27) that I realised how much I had deteriorated after the age of eleven. I can see now how much of a struggle my late childhood and adolescence had been, but at the time I did not see it and so did not commemorate it.

If I were to find artefacts from that period (and I was determined to), I would have to be creative. Eventually, after much searching I recovered three snapshots. Only they weren’t photographs. They were metaphorical snapshots. But they were better than photographs. Two were something I had made at the time and one was something an important person in my life had made. Not only that, but these “snapshots” were all in writing.

I would like to say that I *chose* the three snapshots on which to base my discussion in this chapter. However, I didn’t really have much choice. When I went back through things I’d written while growing up, I found that although there were a lot of pieces (I have always kept my writing), my medical condition was notable by its absence in them. Although I wrote a lot, I was not a very confiding child. I never wrote about my illness in the first 20 years of my life,

except on the two occasions I record here. That in itself says something. Out of necessity the middle snapshot is written by somebody else. I think that says something too. Ironically I have had to borrow stories all the way along to understand my own better.

Whether my resolute silence on the topic of my health was the result of denial, fear, emotional fatigue or a response to the unspeakable I do not know, but as an adult I find it perturbing. I would like to think it was childish ignorance, but I know better. I was there. There are advantages to living in denial – you can avoid pain for a period, you can pretend things are as you would want them to be, you can save others unhappiness. This technique has been used in medical practice for years (Chen, 2007; Good, Munakata, Kobayashi, Mattingly & Good, 1994; Marzano, 2009). I learned it from the best – doctors who work with dread diseases and their effects every day. My silence is, in some senses, a medical one. You were not supposed to cry when they stuck needles in you. You were supposed to be grateful when your condition could have been so much worse. Above all, you were supposed to be brave and show confidence in what was being done to you. You were, after all, fortunate enough to be treated. You cannot believe how devastating it is to find the treatment you adhered to so well and for so long is no longer working.

Narratives perform many different functions: they communicate experience, they (re)construct the self, they mediate the personal and the cultural (Mattingly & Garro, 2000). I have seen in my own narrative that narratives have a way of containing experiences and risk occluding anxiety-provoking ideas (see snapshot one below). So I shall attempt to fill in some of the gaps afterwards. Generally in postmodern writing revealing the gaps, fissures and cracks in narratives can deconstruct the narratives (Derrida, 1998; Selden, 1985). In this part of my narrative(s) there seems to be little else than gaps. Of course, in writing about this part of my life, in creating a narrative from so many gaps, I veer close to normalising and smoothing the narrative (Nelson, 2001; Spence, 1986).

The first snapshot is an excerpt from my school composition and comprehension book when I was nine. This was a couple of years after I started seeing my paediatric renal specialist, Paul.<sup>4</sup> By the time of this snapshot I was familiar enough with the routine of clinic, blood tests and diet. The second is a fragment of a poem a young fellow patient wrote when we were in our early teens, in the middle phase of chronic renal failure. The third snapshot is a description of a dream I had in 1990, not long before I went onto dialysis. I was 21.

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<sup>4</sup> I have changed the names of people I refer to, so that their anonymity can be preserved.

My snapshots are “milestones in a journey” (Muncey, 2005). Although they are part of a journey I have taken, they are strangely unfamiliar to me when viewed from a distance. They were none of them defining moments when I experienced them, but became defined moments when I wrote them down or memorised them. I unwittingly gave them definition when I did this aged 9, aged 12 and aged 21.

### 4.3 Three verbal snapshots

#### 4.3.1 Snapshot 1: Composition and comprehension (1979)

*My best food is smoked salmon, jam-tart and pepper mint (sic) creams and roast lamb. But I have got a high blood cholestrol (sic) and can only eat special diary (sic) products and cut the fat off my meat.*

*(Rose Richards, “Composition and Comprehension”, 1979)*

In 1979 I was four months shy of turning 10. I was in standard three at St Katharine’s, an Anglican girls’ school in Johannesburg. It had been almost exactly nine years since I had contracted HUS. At first, when I reread my piece of childhood writing after an absence of many years, I decided that I must have thought I led a perfectly normal life, because it was all I knew. This must have been why I didn’t mention my kidney problems or the clinic visits or medications. On reflection I suspect that I must have known it was not normal, because I explained briefly what a high blood cholesterol meant in terms of diet as if I did not expect my teacher to know. I also have a vague memory of my mother advising me here. I asked her how to spell “cholesterol” and when I told her why I needed to use the word, she suggested an explanation of what that implied. I didn’t mention the things that caused me anxiety, the terrible and incessant needles, the pills, the clinic visits, the medical narrative of doom that was unfolding inexorably, despite my best efforts.

My teacher, Mrs Livingston, had asked our class to write about ourselves and we obediently wrote out small, wobbly essays about how we looked, who our siblings and parents were, and what we liked to do for hobbies. I listed gymnastics as my hobby and described it taciturnly as “fun”. We were sure to put in a good word about our school. According to me, St Katharine’s was “lovely”.

The parts of the essay on which I spent the most time were my brother (his appearance and proclivity for hitting me “allmost (sic) all the time”) and food. Rather sadly all the foods I listed were forbidden foods in terms of renal diets of the 1970s. Salmon, lamb and chocolate-coated

peppermint fondants contain too much cholesterol. Salmon and lamb are also full of salt and protein. By then my diet was fairly restricted.

I did not hit my brother back. It never occurred to me to do so. He was two years and eight months younger than me. Officially I was the big sister and care-taker. I had been taught not to hit. Privately I knew I was not strong enough to fight back. I was not growing as fast as I ought to have been. He stood shoulder to shoulder with me and was more than my weight. This had been so since he was 4 years old and I was 6 years old and 8 months. We looked like fraternal twins, a pretty little pigeon pair in matching shorts and T-shirts. Dressing alike seemed to pacify him. Maybe he resented the extra attention I got for having to go to the doctor every three months for blood tests, taking antihypertensives and anti-gout medication each day and having to keep to an increasingly restricted diet. Mom worried about me constantly and saw me as frail. If I had the suggestion of a temperature she tucked me into bed. My brother by contrast was seen as tough and strong – a big boy.

Because I was small and slender, I was always being seen as years younger than I actually was. I hated it. It was one of the reasons I had left ballet a few months previously. I had started ballet because my gym teacher had suggested it would give me grace and poise. It was the beginner group. My class mates were 6. I was 9. My ballet teacher had tried to pass me off as 7 to the examiners. I was so outraged I thought I'd explode. This was the worst of many humiliations I had had to endure in her class, from being jeered at by school mates whose younger sisters were in my class to being told that I looked strange when I tried to conform to the discipline's inflexible rules.

For the exam, each member of the class had to do the "Dolly dance" individually for the examiners. It was very formal. We had to walk into the room in a certain balletic way, curtsy to the examiners and be introduced to them by our teacher. We were not allowed to speak. But when she told them I was 7, I whispered indignantly, "I'm not!" The teacher smiled stiffly and repeated, "Seven years old" in a quelling way. I shouted, "I'm nine!" Later, after the exam was over, she asked if I'd be back the following year and I shouted, "No!"

As with ballet, when I read journal now about the food issue, it clearly was a big issue. The diet became increasingly and regularly more restrictive. Food is an inescapable part of life. For more years than I care to calculate, every day, three times a day I forced myself to eat meals I found unpalatable, could not taste because of the toxins that saturated my system and for which I had decreasing appetite. Even today, nearly 20 years after transplant, food is still a weighty emotional issue for me. This aspect of kidney disease is often not understood by researchers, because they have not lived it. Food is beautiful. It has colours, flavours, textures



– and this diet takes all that away. Combine this with the lack of appetite and the way in which your sense of taste changes as you become more and more toxic and you have a recipe for wanting to eat other things. It's also difficult to organise a diet such as this in a normal environment with friends and family needing proper food. That's why the patients in Faber et al.'s study wanted to be normal – not because they felt it made them look sick. That's the outsider interpretation of Faber et al. (2003). I used to fantasise about steaks, while eating matchbox-sized pieces of meat and leached vegetables.

One of the few promises I made myself about life after transplant was that I would never eat anything I didn't want to eat or deny myself anything I did want to eat. I would always eat as much as I liked of anything. I would never diet again. I would accept my weight at whatever it settled at. These promises I have kept. I weigh 25 kilograms more than I did after transplant. I am however still within the normal weight range for my height.

Weight became an issue during my teens, but not in the way it usually is for adolescent girls. My growth slowed down even further and I started to waste away. In my late teens I could pass as a schoolchild between 12 and 14. I could still shop in the children's department. In my mid-teens this used to irritate and embarrass me. In my late teens I found it amusing and enjoyed passing myself off as a child prodigy. I seemed to freeze in time during my teens. I did not grow much. I did not develop much after puberty. My hair and nails barely grew. Even emotionally and intellectually I seemed to not be able to move forward. These days I find it difficult to work out how old I am in photographs taken during my teens and so they would not have done as artefacts. I can usually only guess at my age by my context or clothing. I looked the same for years. I grew after transplant.

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I found my school essay by chance in a cupboard, while looking for something else. I had decided to include it in this chapter for over two weeks before I saw what was missing from my essay: the illness itself. True, high blood cholesterol was the reason I was on a restricted diet, but the reason I had an elevated cholesterol was because I was in chronic kidney failure. At 9 I knew that my kidneys were damaged. I knew some of the work that kidneys do (pass urine). I knew they were vital organs. I knew that means you cannot live without them.

Adults think that children do not understand what death means. This is not true. I never had the comforting illusion of immortality that some people have well into adulthood. As a small child, before I could talk properly and when I was still young enough to be wearing nappies, I used to get croup. This was not long after I had recovered from HUS.

Everyone of us has those dark secrets that only we know about. This was mine. Each night, as I lay in my crib with the high white sides, or later in my little bed, in the dark, I would listen. Not for the reassuring murmur of grown-up voices from beyond the door. Not for the rustling of birds or branches, but for breathing. My own. I knew that if I was not breathing, I would die. I had heard the grown-ups say so. They did not like me to cry. I was not supposed to and I could not talk well enough to explain to them why I was so upset. So I learned not to cry. Instead, I learned to listen to my breathing. In and out. In and out. In and out. Over and over. As long as I was breathing, I would be all right.

There was only one problem. When I didn't have croup, I couldn't hear my breathing. So I used to breathe harder, through my mouth, so that I could always be sure I would survive. I worried about falling asleep too. I would not be able to monitor my breathing. Not to worry. My mother found me some tiny illustrated books of child's prayers and my grandmother would often read them to me. Sometimes we'd read through the book together and look at the pictures. Soon I could read myself. But by then I had already become familiar with "Matthew, Mark, Luke and John". To my mother and others it was just a charming rhyme. To my grandmother it was a comfort. To me it was a death threat:

Matthew, Mark, Luke and John,  
Bless the bed that I lie on.  
Four corners to my bed,  
Four angels round my head:  
One to watch and one to pray,  
And two to bear my soul away.

(Tudor, 1964)

Life was never something I could take for granted. But I veered between struggling to stay alive and simply accepting that clinic visits, blood tests, restricted diet and medication were a normal part of my life. For a long time I felt normal. Chronic disease can be like that. Inside me my kidneys were atrophying, but this did not hurt. Slowly, very slowly, my body was filling up with creatinine and urea. My kidneys could not filter these toxins efficiently as their glomeruli (filtering parts) became scarred and thickened. And my kidneys began to shrink into themselves as their inner workings gradually ceased to function.

I was losing a set of vital organs and their gradual demise was being charted by my doctor every three months. Each time I went to him I came away with more dietary restrictions, different blood pressure medication and new instructions regarding the decreasing amount of exercise I should do. I simply gritted my teeth and went along with it all. I did not feel loss so much as limitation, restriction and deprivation. I felt my world getting smaller as I got bigger.

Restriction was counter-balanced by my own physical deterioration. My appetite diminished and my growth slowed. I was always tired. It did not matter after a while that my food was boring. I could not really taste it. I did not want to run around a lot or go out late with friends. Social events took too much energy from me. So I did not develop a desire to go to parties and drink alcohol or experiment with drugs. I stayed home with my books. I suppose in some ways kidney failure made me who I am today.

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Here is what I remember about my diet in those early years. It was to become very much stricter in the next decade. In 2007 I started writing a journal about what I remembered of those times and to make it easier to begin telling my own story, I began with the medical parts that dominated my life for so long. Food featured prominently in my journal:

*The renal diet was a bit of a shock. It started out as fairly low protein, very low salt and very low cholesterol. Mom consoled herself that this was a healthy way of eating, but it essentially meant that our household cooking had to change. I remember my mother being flustered and anxious, trying to work out what could stay and what had to go. Essentially dairy products and meats were out, and so were foods that had preservatives. We had never eaten much junk food, so this didn't matter. However, salt could also be found in cooking spices, baked goods, biscuits, most recipes and, well, table salt. No salt on your food at the table. No salt in the meal as it was cooking. No salt on your popcorn in the movies.*

*Mom decided the easiest way of doing things would be to have everyone eat a low salt and low cholesterol diet. It was, after all, healthier. She didn't think she could restrict everyone's protein too though. My father liked his meat and my brother was growing. So was I. She worried about my brain development, but went out at once and replaced our food with low fat and salt free food and threw out the newly unhealthy foods. She also threw out her recipes that were no longer healthy. She liked to cook and tried to make a challenge out of cooking without salt and cholesterol. It was a bit more of a challenge than she bargained for and she found her repertoire shrinking. She also found it was not practical to present guests with low fat, low salt dishes. We could get used to flavouring our foods with herbs and not salt or fat, but guests needed the real thing. So apparently did my father.*

*They used to fight about that. He would cut the fat off his chops with surgical precision before my renal diet started. Now he was fantasising about chickens roasted in butter (which we no longer kept in the house). And baking didn't taste the same with low-fat*

*margarine. Nonetheless my mother continued to discard the unhealthy foods from the kitchen cupboards and the fridge.*

*I was recruited to help her. It was for my own good, she told me. I had to know how to look after myself. I remember her crouching down in front of the deep cupboard that held a type of carousel which you could spin around to reach things at the back. She had a black dustbin bag, filled with packets of this and sachets of that and she was industriously tossing into it more malefactors, after checking their ingredients and nodding, “yes, salt” or “protein, of course, and that means cholesterol too”. There was not much left at the end.*

*So she bought new stuff. Margarine for butter. Low fat milk when it became more readily available. Egg powder for eggs. Orley Whip<sup>5</sup> for cream. She tried to make my food as interesting as possible, but Orley Whip doesn’t taste anything like cream and I came to hate the mocking whoosh as it puffed out of its can onto my tinned peaches. I soon decided I’d rather go without cream at all than endure Orley Whip’s oily froth anymore. There was also junket and blancmange. They were horrible. The egg powder was pretty vile too. It came in plastic bags, inside little cardboard boxes, with its own yellow plastic scoop. I cannot for the life of me remember what it was called, only that its name was a grisly pun. I soon deleted that from my diet. Mom saw it as ungratefulness. I had to make an effort, she would shout at me, after all, she couldn’t do it on her own. I had to take responsibility. I was seven. I tried. I really did. I notice searching the internet now that there are other things you can use to substitute for eggs – oils, bananas, even baking soda. We didn’t do that though. I remember her scoffing at that as desperate and unappetising. I think my mother wanted to keep things as much the same as before the diet as possible. But food gets into everything and every aspect of your life. You have to eat three times a day every day. There is no putting it off.*

*There were other things I couldn’t have. I remember being invited to a birthday party around that time – maybe a year later – and Mom was discussing the party with Paul. I was lying on the examination table, watching the patterns of blue hospital initials against white starched sheets. They looked like flowers. I had looked at the neon lights in the ceiling and the rungs of the curtain which was never drawn around the examination table. It had a different pattern to the sheets. Stripes, I think. The top sheet was worn and its edges had started to fray. It also had a bit of red ink on it from the laundry stamp. It was very clean. I could hear big people walking about in the corridor and nurses talking to each other. It was a funny thing about the paediatric renal clinic. You never saw other kids.*

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<sup>5</sup> Orley Whip is a non-dairy cream alternative.

*"It's quite all right for her to go," he told her. "She must just be careful not to overdo it. The weather's hot and she mustn't get dehydrated."*

*"Did you hear that?" said Mom to me. "You must drink lots of fluids. Every half hour."*

*"Every hour would be enough," said Paul.*

*"Can I play games?" I asked.*

*"Yes, just don't let yourself get tired. Rest in between."*

*"So you don't put strain on your body," said Mom. "Don't let those kids run you into the ground!"*

*They never did. I used to run them. I was going to say so, but decided against it. I knew what was coming next, but it was worse than I imagined. And it wasn't bloods.*

*"Be careful what you eat," said Paul. "No egg sandwiches..."*

*"I don't like eggs," I said, relieved, but he continued.*

*"No chips, no ice cream, no nuts, no cookies, no Niknaks.<sup>6</sup> You can eat sweets as long as they're not chocolate, no ..."*

*I assessed each treat as it passed me by. I loved chips. I quite liked ice cream. I enjoyed nuts. I couldn't care less about cookies. They were in the egg sandwich category as far as I was concerned. They took too much chewing I loved Niknaks too. I liked chocolate, but could do without it. However, sweets in general didn't interest me much. Where was this going to end? What sort of a party would it be? I would have to sit in the shade watching other children play and then stand at the edges of the crowd watching them eat. I wished Mom had not told him about the party. I felt more stressed as each item rolled off his tongue. By the time he got to Niknaks, I was still clutching chips, and something snapped.*

*"Can I have any birthday cake?" I blurted out.*

*Paul stopped his list and looked at me with melancholy eyes.*

*"I don't know what the icing will be," I mumbled. "It might be butter or it might be royal. Maybe it will be an ice cream cake. Michele had one last year, with a Barbie doll in it, but I don't know. It wasn't all ice cream. There was a sponge cake inside, but the ice cream was*

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<sup>6</sup> Niknaks are a type of puffy corn chip.

*thick and pink and white, in ruffles, like a skirt. So it's not solid ice cream – it might not even be real ice cream. It might be like Orley Whip, but thicker and I could maybe have a small piece...*

*"Of course you can have birthday cake," he said rather sadly, I thought.*

*I wondered if he were disappointed in me for not "playing the game", as Mom would call it, and making the best of my new restrictions. He didn't seem angry.*

*"Just have one piece though," he said.*

(Richards, undated journal entry, 2007)

*I think I secretly believed that if I kept to my diet I would get better and be rewarded with treats whenever I wanted them, like other people had. I would at last be allowed to be carefree, the way my friends were. I didn't feel unwell – at least not that I was aware of. But my disease was a wasting disease and it was insidiously wearing me away. My slow growth was an outer sign. So was my slenderness. My pallor. I used to get sick quite easily and I notice, looking back over my school reports how often I was off school. It was easily twenty-something days in the year. To be honest I wasn't always at Death's door. If I didn't feel perky or enthusiastic about the day's classes I could easily talk my mother into keeping me home. Sometimes she even suggested it.*

*...The treats I used to get when I was sick were often cheating treats. Chips, salty packets of soup, chocolates, cheddar cheese. Chocolate digestive biscuits. As my diet got stricter and my mother more frantic, Paul suggested we cheat sometimes. In fact he strongly advised it.*

*"Are you sure it's all right?" my mother said dubiously.*

*"Yes, it's healthy and keeps one going," said Paul. "Go out for a treat once a month and let her eat whatever she likes."*

*So we did. When I was in high school, Mom used to pick me up from school on my early days (usually a Tuesday) and we'd go to one of several coffee shops in Rosebank or Sandton and have something special. At the Oslo, we'd have venison soup and homemade bread and butter. At Steffanie's we'd have meringues and cream (real cream). At the funky sports place in Sandton, we'd have non-alcoholic tomato cocktails with salt and pepper and a bowl of raspberry gelato. At the Sandton Sun hotel, it would be rock shandies and shrimp cocktails. It was like Christmas, but without the anxiety.*

*But I can eat them now. Mom's story would be one of triumph – look what I can eat because I did what I was supposed to do. Mine is one of scarring. I still feel like looking over my shoulder if I buy chips. I still am eaten by guilt and a combination of thrill and anxiety. I eat a lot of things I “shouldn't” now. I wonder how my arteries are. Sometimes I go for cholesterol testing. It's slightly above what is considered desirable, but it never changes. For me that means it never gets higher. Considering what I eat, I would be very surprised if it got lower.*

(Richards, undated journal entry, 2007)

Something I had not mentioned at all in my composition and comprehension book was something that for most people is a clear and unmistakable trapping of illness and to be resisted at all costs: pills. I have taken them every morning of my life since I was seven years old. I still do. The pills change over the decades, but the routine does not. At the time of writing the piece about the food I liked, I had been taking pills for almost three years. I wrote about pill-taking in my journal:

*Pill-taking is a field of study on its own. How patients with chronic medical conditions take (or don't take) their medicine is especially interesting to doctors and pharmacists. Compliance in pill-taking is a big area of debate.*

*I know, when I was growing up, that my doctor was very concerned about lack of compliance amongst his adolescent patients. He used to lecture me about it, while he took my blood and did my obs. He used to tell me that when people became adolescents they became rebellious and would even do things that were not good for them. He told me about teenagers in his care who had lost their kidneys because they had stopped taking their pills and sticking to their diets. I stuck to my diet and never missed my pills. I took small amounts of different beta-blockers (antihypertensives whose dose changed over the years) and Zyloprim for my gout. I only lost my kidneys in my early twenties.*

*I could never understand why other patients were so emotional about the pills. They didn't taste of anything unless you held them in your mouth for too long. Then they tasted bitter, but a few sips of water and a quick swill would take it away. They took seconds to swallow. Apparently taking them made some people feel bad about themselves and to see themselves as defective. I found this strange. I did not feel defective particularly and I reasoned that we were taking pills because we were ill, not ill because we were taking pills. I suggested my doctor explain this to his other patients, but he looked sceptical about it.*



*After I moved to the adult unit at nineteen (my doctor hung onto his patients as long as possible and told me he'd look after me until I was 25 if my kidney function held out, but it didn't), I noticed that adults were even more fussy about their pills. They never liked them. Never liked taking them and complained about them constantly. Especially about the side effects. I thought they were babyish. I kept on taking mine. I had had some side effects in my last couple of years at school, but my doctor had changed my pills to new ones that didn't have side effects. Of course the doctors on the adult clinic didn't listen to us as carefully as my doctor did. This might have been part of the reason there was a problem...*

*So how did it begin? Almost as soon as I had seen Paul for the first time, at seven, I was put onto antihypertensives. My blood pressure must already have been elevated. I felt pretty much as I had always felt. While taking the pills, I felt as I had always felt too. My mother found a baumanometer to read my BP at home. It was in a silver metal case, the length of a loaf of bread and had a silky grey blue cuff that wrapped around your arm. The cuff was very long, like a scarf and the part of it nearest the two rubber tubes contained an inflatable rubber pad.*

*...The BP pills were not designed for children either, but luckily Paul had years of experience in calculating the right doses. All I needed to take was a quarter of one tablet a day. This meant of course that the pills had to be cut into quarters. Breaking them in half was easy enough, because they were scored down the middle. You had to be careful though to break them evenly. With such small doses, two thirds instead of a half would drop my blood pressure to a dangerous low. The trick was to take a heavy-bladed knife, with a sharp point and to rest the sharp point in the middle of the score mark, push it in and chop. That was the easy part. Once the tablet was halved, the difficult part came. It now had to be halved again and this time with no score marks. It was impossible to break it into quarters, even with Mom's strong fingers and tough nails. My fingers were too little and my nails too soft and flaky. They just broke or peeled if I tried. So we had to practice with the knife again. It took quite a lot of trial and error before we got the knack.*

*A couple of years after I started with Tenormin, I had to start taking Zylprim. It was for gout. Uric acid crystals were accumulating in my joints because my kidneys weren't filtering uric acid out of my system efficiently. My joints were sore, especially my ankles. They felt hot too sometimes and even swelled up a bit. My mother said I should tell Paul, so I did. At first he said they were growth pains, but I wasn't growing very fast. I told him so. He felt my ankles.*

*... To my dismay, Paul said he was going to draw blood. More blood. He'd just taken some. I hated having blood taken. Maybe he was cross about how I'd spoken to him. I wanted to cry.*

*Yes, something else I didn't mention in my school essay was blood-taking. I could manage the clinics, the examinations and the pills, but the blood-taking defeated me time after time. Even today the thought of needles makes my insides quiver. I do find it interesting that I refer to my cholesterol levels as "a high blood cholestrol". It is medically accurate (other than the spelling), but usually one talks informally of a "high cholesterol". The blood leaked into my thoughts anyway – and with that, how it was taken out of me.*

*... The result of that particular test was that I did indeed have elevated uric acid levels in my blood. This meant that I had to be very careful about the protein I consumed, so there was less of that than before. I loved meat. I couldn't believe it. I wished I hadn't mentioned it.*

*It also meant that I had to take Zyloprim. These tablets were white and small and didn't have to be broken. I took varying amounts of them because we never seemed to be able to get the doses quite right, although they were apparently easier to adapt for children. I also remember Paul examining my skin minutely after I started taking them. He'd start by looking closely at the backs of my hands and then my arms. He'd look at the skin on my stomach while palpating my abdomen and skim over my legs, paying close attention to my ankles and feet.*

*I see, researching Zyloprim, that the most frequent adverse reaction to Zyloprim is "skin rash". Furthermore, "skin reactions can be severe and sometimes fatal". My source does not say how... Terminal rashes must have been what he was looking for. All he ever turned up were spider nevi, little red spots like pin pricks on the backs of my hands. These can be the sign of an underlying systemic disorder, especially if there are more than five, but there seems to be some debate about how reliable an indicator they really are of, for instance, liver disease, since healthy children often get them too. Nonetheless, Paul wasn't taking any chances. We counted my spider nevi and tested my blood, adjusted my doses, felt my ankles. Mom put me on multivitamins too.*

*And so we continued until my mother became seriously ill when I was nine. She developed septic arthritis and spent several months in hospital. My brother and I went to stay with her parents. They took me to clinic every three months, collected my prescription every month and Granny and I handled my medicine at home. Mom had always made sure that I knew*

*what I took and how much, although she'd done most of the cutting. She'd also monitored my taking the pills every morning.*

*Now Granny did that, but she was old and frail. Her sight had almost gone completely and she walked with a white cane. She had a lot on her mind, with Mom being so ill and I didn't want to worry her, so I made sure I remembered my pills each morning. This meant that when she asked me about them at breakfast I could tell her I had already taken them. This made her look pleased, so I developed an elephant's memory about them and never missed a dose. If she forgot once in a while to ask me at breakfast if I'd taken them, I would remind her to do so or mention that I had, in fact, already taken them. I also found myself cutting the pills. It was rather boring, but we decided that I'd sit down at the kitchen table immediately after coming home from clinic, without even changing out of my school uniform, and start cutting up the Tenormin.*

*Granny would fetch the cheese board and the knife. I had to tell her which knife would work best (not serrated, pointed tip), although their knives were not the same as ours. And off I'd go. It could take an hour. Granny would talk to me while I cut and she'd get started on the supper preparations. She was a teacher and I was her eldest grandchild. She would ask me about school and test me on my homework. Or we'd talk about what I'd been reading or the adventures my toys were having. Most of my toys were animals that behaved like people, wore clothes and talked English. She would make them little notebooks so they could record their thoughts (inscribed, "To Pink Panther, with love from Granny") and would remember all the things they got up to between our conversations.*

(Richards, undated journal entry, 2007)

I was a great one for not mentioning things. Interestingly I seem to recall that I wrote the essay of this first snapshot while waiting in hospital. Not for my turn at having bloods taken, but for visiting time to see my mother. She had been admitted for septic arthritis and nearly died. I wrote it kneeling on the floor next to my grandmother in the waiting room at Sandton Clinic. I have a very strong memory of doing this, but I could have sworn that my mother had been ill the previous year.

#### 4.3.2 Snapshot 2: Blood and urine (1983)

*Buckets full of urine*

*Syringes full of blood.*

*If a little extra*

*Feed the geraniums in the mud.*

(Eddie Davidson, c. 1981)

I am not present in this snapshot, although it conveniently falls roughly midway between the other two. Why include it at all? I included it because I wanted to make a point and by so doing I am deliberately shaping this part of my narrative. I am also undoing what I set out to do in the first snapshot, where I tried to recover my own lost story in the face of the stories of others with which I was constantly assailed. My story is once again being told through the stories of others. This may be postmodern, after all, as I am transgressing my original “law” (Selden, 1985) to tell my own story and not work through the stories of others. It is certainly expedient. After all I wrote very little about my medical condition growing up.

The poem is by a fellow patient at the paediatric renal unit of the Johannesburg General Hospital. I would have been about 12 at the time it was written. I never met Eddie, although we were treated by the same doctor and were patients at the same unit for roughly the same amount of time. He was about a year and a half older than me and had his first transplant at 8. Our doctor’s consulting room walls were covered by pictures and poems from his little patients. Most of the contributions were from Eddie at the time of his second transplant. He wrote on pumpkin-yellow paper with thick felt-tipped pens. Sometimes he illustrated his poems with pictures of bright flowers in pots and round-eyed, smiley faces peeping over window ledges. The poem above was only one of his contributions.

When my mother saw Eddie’s drawings and poems she urged me to contribute something too and I said I would. But when I got home I couldn’t think of anything to say. Eddie seemed to have said it all. I was impressed at his daring, writing about blood and especially about urine. From my experience people preferred one to stay away from those topics. I used to write about death a lot, usually violent, premature death and that seemed to get some (but not all) teachers, classmates and parents riled up. I had a feeling they’d riot if I started to splash about in urine too.

Writing about urine was a taboo. You were not supposed to do that outside hospital. These things were unmentionable, dirty and shameful. We seemed to behave as if we did not have bladders or bowels outside the Johannesburg Gen. I did not succeed in sustaining this illusion, however. I still remember my shame when my bladder leaked all over the floor in the locker room in 1983. I was playing the fool with two friends and was laughing too much. I used to struggle with incontinence in adolescence. I haven’t had a problem with it since transplant and since I stopped losing protein through my atrophying kidneys. At the time I thought it was my fault. Now, as an adult, I see that it was probably part of the wasting away of my body. No one ever explained this to me. But of course I never told anyone, not even my doctor.

The shame I felt at discharging what seemed like buckets of urine onto the locker room floor caused my body to become apparent or visible, but simultaneously in Leder's (1990) terms to disappear. Adolescence is a time of great change and great uncertainty even without any other challenges. That my physical challenges were never fully articulated and, therefore, never fully explored, did not lessen them. Instead it increased my self-doubt and decreased my feelings of competence. Possibly I never had the courage to write about buckets full of urine myself because I was trying to keep them out of the public eye.

I felt anxious about the syringes full of blood too. I was more needle-shy than ever, after experiencing so many more of them. I preferred not to think of needles when they were not being stuck in me. I knew they were the way to test my kidney function and so I endured them every three months. I learned to quell my burgeoning fear about them, which started to grow about ten days or a week before each clinic visit, by diminishing the experience in my mind: "It's only a little needle – you will hardly feel a thing".

Paradoxically that made it worse. I could act brave and not flinch when my doctor put the needle into my arm, but I could not fool myself. Outside I looked stoic and calm. Inside I was gibbering. My mother urged me to think of happier things to take my mind off the dreadful eventuality of the needle piercing my thin and easily-bruised skin and so I pretended that I did, to keep her happy. But really the closest I got to achieving that meditative state was to let my panicked mind go blank and to disappear for a while. This type of disappearance prevented dysappearance.

*Paul always took my blood himself, except on the occasion a student doctor did it. I think Paul was on leave then. It was the only time in 12 years. I don't think the doctor was used to working on children. He seemed befuddled by our small arms and little blood vessels. He probably felt anxious about having to stick needles in so many reluctant and unhappy little children. He decided the best way of handling this would be to keep a wall around himself and not to let anything in. This meant he kept his face expressionless and held our arms firmly and unrelentingly as he jabbed the needles home.*

*He jabbed the needle through little veins, right through both sides, and sucked the blood out of our tissues, despite our tearful protests. He found it very hard getting blood out of our arms. I told him he was hurting me, but he ignored me and went on doggedly pulling on the syringe, whose contents seemed to hiss and bubble.*

*"I think you've missed the vein," I gasped at last.*

*"I put the needle in it," was all he said.*

*He didn't even look down, but kept staring woodenly at the wall as he pulled on the syringe. I felt cheated. I had been psyching myself up for months to being able to watch the whole process.*

*I had reconciled myself to the fact that I would be having bloods every three months possibly for the rest of my life. I had broken the blood taking into stages: 1) Paul selecting phials from the polystyrene tray and picking up the syringe, 2) Paul taking the needle out of its sterile case and putting it onto the syringe, 3) Paul putting the syringe down and checking the baumanometer's cuff was firmly in place, 4) Paul tapping my distended vein and swabbing my arm with hibitane, 5) Paul picking up the syringe and ... I had managed the first four stages remarkably easily. I experimented with each one for a clinic or two to feel confident about it. I didn't tell Paul or Mom, deciding I would surprise them with my success when I finally managed to watch the whole procedure with an unblinking eye. I got a bit stuck on stage five, but Paul kept such a routine, that I could calm myself down through its inevitability. I comforted myself that although I could not actually watch him push the needle into my vein yet, I soon would. And I no longer cried about it. I was after all 15 and about to be grown up. Enter Student Doctor.*

*I have never been able to watch the whole process. I ended up with a bruise the colour of midnight that ran from half way up my bicep to half way down my forearm. I looked as if my arm had been run over by a car. It took five weeks for it to turn brown. I told Paul. He looked grim and said the doctor would not be coming back and that there had been problems with other patients too. Paul's colleagues were not more important than his patients.*

(Richards, undated journal entry, 2007)

My nose started bleeding around this time. At first the nose bleeds were not too bad and occurred only every couple of weeks, but over the years they increased in frequency and severity until I was bleeding from my nose several times a day. The last bleed lasted two hours. I couldn't get it to stop until I went to a doctor. I had to have my nasal blood vessels cauterised. It might have been partly due to my steadily rising blood pressure. It might even have had something to do with that missing clotting factor that was possibly a result of HUS and its impact on my liver. I still bleed spectacularly today if I have to take a pinprick test, but at least it's not from my nose.

It was also around this time that I finally asked Paul whether I could ever get HUS again. I never used to care what caused my illness; I was more interested in taking preventative measures to ensure a good future. I could not remember anything about when I contracted

HUS and everything I knew came from my mother's short, dramatic accounts of how I nearly died as a baby and how terrified she was when I started having seizures.

It makes aesthetic sense and has a pleasing feeling of symmetry that my nosebleeds might have been triggered by some type of cellular memory of my bout with HUS. It took me a while to think of the connection, though, and I have to concede they were more likely triggered by dry, Highveld winters...although no one else in my family ever had them and presumably we have the same sort of nasal passages. And it wasn't always winter, certainly not during that year my nose bled several times a day. Is it my anxiety that prevents me from accepting the connection between HUS and my spontaneous bleeding? Or it might be healthy scepticism? Another subjunctive (Good & Good, 1994) – another unanswered question, another unresolved issue. With my medical condition, seldom can cause be determined (no apparent ontology). Is this liminality or littorality? It causes me disquiet, so it feels liminal, but it has lasted all my life and I suspect it is simply how things are. It is part of living in a third space, the littoral zone that makes me unsettled there.

At the time I was bleeding I simply viewed it with a mixture of annoyance and amusement. Blood itself has never bothered me. Although it did bother me to wake up in the cold, grey morning covered in it or to be sitting in the bath, preparing to get out and dry myself off, only to have to bath all over again to wash off my own gore. The meaty smell that clung to everything was not particularly appetising either when I remembered where it came from.

#### 4.3.3 Snapshot 3: *Unquiet dreams (1990)*

*I dreamed there were 2 bright green + yellow vegetables the size of yams in my bedroom. But they turned out to be chrysalyses (sic). They hatched into 2 large (+/- 3 foot long) silkworms, white and wriggling. I stared at each revolting part of them, especially their horrible short fat legs. But parts of their bodies kept erupting into new worms, attached to the old ones. In the end the monsters behaved rather like hand puppets.*

*(Rose Richards, Dream Diary #1, August 1990)*

Dreams are part of one's narrative and can be included as part of an autoethnographer's resources as a conduit between worlds (Poulos, 2009). Dreams lie in one's mind, between sleeping and waking, but sometimes they fill one's body too and it responds as if we were really there. Dreams are how the mind interprets problems and situations, when left unguarded. Hermes was a trickster god, but also the bringer of dreams. He could move between worlds – sleeping and waking, the living and the dead.



Kidney failure can cause some rather colourful dreams. This is partly due to the toxins in one's system. It may also be due to fear. It is tempting to interpret this dream not as the result of having too much creatinine and urea in my system, but rather in terms of how I felt while dreaming it. I felt as I felt while awake: terrified.

By this stage I was so ill that I was not able to continue my studies. Fortunately I had completed my bachelor's degree at the end of 1989. I had entered into a dark valley in my life since leaving high school. Part of the way through my first year at university the year I joined the gym club, but failed to attend any classes in it due to extreme tiredness, lack of energy and weakness. I soon discovered that I was no longer strong enough to climb stairs. I had to force myself to eat every meal. It could take me an hour to eat a piece of toast. I had no appetite and my muscles were wasting because of all the protein I was losing through my urine.

My heart trembled and hiccupped – a problem with my mitral valve, my paediatrician said. I was still seeing him; he kept me in his clinic until I needed dialysis so he could spare me the horror of the adult renal unit as long as possible. My thyroid had imploded spectacularly and haemorrhaged into itself until it was the size of a hen's egg and had to be surgically removed. My throat muscles didn't work properly. My nose bled every day several times. I still have a blood-spattered little fabric pouch from those days in which to keep tissues. I was covered in bruises. I was always cold. I was always thirsty. I could drink eight litres of fluid a day and it would run right through me. I learned to keep my bladder empty at all times, because of my unreliable urinary sphincter. My arms were like sticks. I could count my ribs up into my armpits. People at university thought I was anorexic. I seldom thought to tell them that I was in organ failure, possibly because my mind was hazy with toxins, but also possibly because I knew they wouldn't understand. They hadn't on so many previous occasions.

I used to go to sleep at night afraid that I would not wake up in the morning. Sometimes I sleepwalked and ground my teeth so hard that my dentist made me a bite-plate. Sometimes I would sit down on campus half-way between class and the library and my legs would become cold and hard and alien, like iron, and I could not get up again. So I would sit for hours, staring at the pigeons and the students, telling myself stories I was too feeble to write down. They were good stories, entertaining, fun and always optimistic and they never involved my life, my death or my medical condition. They concerned entirely fictitious people who lived very far away from my problems. I was slow eating, dressing, walking. I learned to pace myself. I learned to slow down the pace and change my plans so that I never needed to back-track on campus. I learned to keep smiling and not to talk about it. No one knew unless I told them. Showering and bathing were the most energy-consuming activities I could undertake. They were even worse than walking. What I decided to do in terms of grooming decided the course

of the rest of my day. I was sleeping up to 14 hours a day by third year. Nonetheless I got my first degree in three years, because all first-year students had been told that most (normal, able-bodied) people didn't. Well, I showed them. I don't think anybody noticed, though, other than my mother.

I did have another activity. I used to spend a lot of time with people who had a range of disabilities. This was partly because I enjoyed their company, but also because I identified with them and their otherness and daily struggles. It was paradoxically and simultaneously because I didn't identify with them. Being with them made me feel more mainstream and grateful for my relative (according to me) good fortune. After all, I could have a transplant and end this awful twilight state, while a person in a wheelchair or who was blind could not.

But by 1990 my optimism was starting to crumble along with my body. Three years down the line and I was no closer to dialysis or a transplant than I had been in 1987. It showed in my dreams. This dream, the one with the worms, was the worst. In my dream diary of the time I described the worms as silkworms. I am not squeamish about creepy-crawlies except for caterpillars and maggots. Honestly, these dream worms looked more like maggots (but I couldn't write it at the time because it was too close to death) and they came out of the yams as if from something rotten. When I wrote the dream down in 1990, I also wrote a question: "Like kidneys?" I was referring to the yams. I found it significant that there were two of them and that they were rotten.

My dreams of that year were filled with dread and helplessness. Paging through my dream diary I see an endless succession of dream tigers eating me, dream lions prowling around me, dream scorpions swarming over me, a dream version of my brother stabbing my pancreas with a giant needle, pythons becoming poisonous and killing my cats (significantly two of them), vampiric aliens abducting and draining the blood of everyone who crossed their path, giant needles shoved into small, helpless and dying animals, my home turning into "the clinical lab where I have my bloods taken", living people dying unexpectedly and the dead coming horribly back to life. All the while in the background lurked a sense of doom and imminent tragedy. Often I would wake with my heart pounding and hiccupping; sometimes I could not wake, no matter how hard I tried. I started sleepwalking, maybe to escape from my dreams. But I could only escape into a waking life that was as dreadful.

I recorded all of the nightmares. They fascinated me macabrely. I wanted to know what they meant. I honestly could see no connection between my medical situation and this endless succession of gory attempts on my life. So I wrote them all down, hoping that time would reveal their truth to me. I would like to think that I had some premonition that I would study

them one day, make sense of them, or that even one day I could bear to look at them more closely and acknowledge what I secretly knew – that they were more than the detritus of a mind saturated with toxins. They showed my experience more completely than any diary ever could. I lived in those places more fully than anywhere else in my ghostly existence towards the end of my descent into kidney failure. I do not recall whether I nurtured any such hopes at gaining clarity. By then I had become so ill and so weak that I seemed to hang between the living and the dead, with one bony foot in each world, my body shrinking away as I lost protein, my hair and nails no longer growing. Nothing was clear anymore; nothing was predictable. My main questions concerned whether or not I could make it to the bus stop, walk to class or manage an evening shower.

Chronic illness, especially kidney disease, is not usually “a series of disconnected shocks” that Broyard describes for acute illness (1993, p. 19). No, everything was connected for me. The common themes in my sleeping world of the time are clear and clearly connected to the waking world I vaguely inhabited. The subtle violence of my body’s deterioration and the not-so-subtle violence of my medical care merged into forms I could still understand: big animals and needles.

It is dangerous to try to make a dream mean something. What it “means” in sleeping life may differ vastly from what it means in waking life. In those days my waking life was so filled with fear and physical torment that all I could think about was my state of health and where I was headed – organ failure. Of course, now, all I can do is say what the worm dream signifies to me twenty years later. For one thing I think it is significant that the dream took place in my bedroom, my private space. Although I don’t say it in my dream diary I remember the yams being on my bed, half-way up and side by side, in the position my kidneys would be in my body. I remember them looking vaguely kidney-shaped.

The dream took place at night, in my sleep, but also played itself out in a place associated with night-time and sleep. I think this is significant. Night-time and sleep can be seen as liminal states. Chrysalises are symbolic of liminality too. Dreams can be seen as a place of liminality, of porous borders and the leaking of a story from one domain to the next, or a littoral zone where things can blend, a third space. And I as interpreter of my dream am a type of mediator between past and present, event and reader. So I, too, as narrator, could be seen as liminal or perhaps a type of “third” entity, mediating between the me of the past and the me of the present.

Sometimes, in those days, if I was feeling particularly desperate or despairing, I would premeditate a special type of treat: half a litre of full-cream milk. I would think about it on the

bus to university for the duration of the forty-five minute trip and once I had staggered up the small hill to Senate House from Jorissen Street, I would lurch into the canteen and make straight for the tetrapak shelf, choose an unflavoured milk and rip open its waxy container. There is nothing as nice as ice-cold milk and I would gulp it down in a couple of minutes. I was always thirsty. The thirst of kidney failure cannot be quenched. Then I would sit back and wonder how much damage I had done. I would hope that it had been substantial. Maybe this time my kidney damage would be severe enough to allow me a space on dialysis and the horrible suffering and limbo could end. Sometimes I hoped it would kill me. Death by milk. And then, something I could never dream of happened:

*The diet got better – deep frying and lots of Coke – seven or eight litres a day. Suddenly the salt, protein and cholesterol didn't matter anymore, but the potassium still did, because it could affect my heart or cause seizures. A normal potassium is 4 or 5 (units). Mine was over 40. It seemed small compared with my urea and creatinine. A new and tasty addition to my diet was Kayexalate (sodium polystyrene sulfonate, according to drugs.com, so it really is made of polystyrene). It was a powder that somehow sucked potassium out of one's body. Even with my altered sense of taste and smell this was truly horrible. Not only that, but it was so fine that it was almost impossible to swallow. At first we naively mixed it with water, but it wouldn't dissolve. Then we tried fruit juice with the same results. At last a nursing sister told us that you could buy a type of thick sugar syrup from pharmacies and that the powder would mix into that and be swallowable. It was just bearable. It became a thick grey-white paste that I could just force down my protesting throat. I tried to swallow it in huge blobs, because that meant there would be fewer mouthfuls. It was terribly sweet and artificial-tasting. I wondered what would happen next, but I was old enough to know without being told. Your body knows too, when it is reaching the end of the road. I was 21.*

(Richards, undated journal entry, 2007)

#### **4.4 What the “album” means to me now**

##### *4.4.1 Snapshots as pieces*

Any photograph album shows only some of the story (Frank, 2010). Snapshots are frozen moments extracted from their context and arranged in an order that pleases the person whose album it is. So it is with mine. If we believe that a photograph shows us the truth (Cook, 1996), we forget it is a representation, part of a larger truth. The picture that emerges is a construct. My narrative snapshots are only that – snapshots. To what extent they can reveal something about my experiences is debatable. They do, however, now reveal something about my

present understanding of those experiences. In years to come that understanding might be different.

These snapshots are aides de memoir that evoke long-buried feelings in me and allow me as an adult to see another view of my childhood and adolescence. Generally the photographs that make it into the album are the ones that show us on our best behaviour, dressed in smart clothes or comical “candid camera” shots. People making albums want to remember cheerful or empowering occasions that help to create an identity that is in some way composite. That was my direction at first, although I had little choice about the snapshots.

However, seeking a composite, empowering identity through fragments of the past was not so simple in practice – nor was it desirable. As I was to (re)discover in the course of my journaling, children with kidney disease face serious challenges that affect their lives and identities: periods of acute illness, small size and dietary problems. This can be seen in the study of Nicholas et al. (2011). The children’s constant sense of dread, of never feeling safe, of knowing that disaster is only a heartbeat away, lurks like a crocodile under the surface of Nicholas et al. academic narrative. They discuss the impact of the challenges on forming relations with peers, participating in developmentally relevant activities and general quality of life. Having no point of reference, I cannot imagine how my life might have been if I had not had kidney disease. Unlike the children in Nicholas et al. study, my mind has always shied away from imagining how it might have been, even when I was a child. Each time I start imagining it, I find myself saying, “But that is not how it was.” As much as I enjoy imagining stories, I do not ever allow myself to imagine that one, not even now. For instance, I find it difficult forming relationships with people my own age. To what extent is this the result of my condition and to what extent the result of my personality?

The children’s narratives are “paradoxical and dynamic” (Nicholas et al., 2011, p. 9). Those words capture the experience of renal disease for me too, but in gathering up this long-buried part of my life I find myself falling in some ways into the (as I see it) trap of coherence, of making sense of the experience. I am, despite myself, repairing a damaged identity (Bury, 1982; Frank, 1995; Mattingly & Garro, 2000), an identity, ironically, that has been damaged by not acknowledging the impact my medical condition had on my life. I shall never know how great that impact has been, but I do know that I am who I am partly because of what I experienced in ESRD. Nonetheless, despite this experience being part of my everyday life growing up, I have discovered in telling (part of) the story of this period of my life, that I had previously rendered it invisible. I silenced it and I silenced myself, because the topic was simply too big for me to cope with.

#### 4.4.2 *What was not in the snapshots*

As a photograph is part of a bigger picture, a narrative is composed of smaller narratives and is in turn part of a larger one, and so, by necessity, can never be complete. As with life itself, the parts of my narrative cannot be seen in isolation from the other parts. Some themes will carry through the other chapters and what might be discovered there could reinforce or undermine what has been seen here. There are two things, two very big things, that cannot be seen in these snapshots: what it was like learning that my efforts to preserve my kidney function were in vain, and what it was like transferring to the appalling adult renal unit where I actually became 548820. I notice that I left them out of this part of the story. These events were the closest I came during the long, slow decent into organ failure to experiencing Broyard's (1993, p. 19) "series of disconnected shocks", as he describes the experience of acute illness.

Being told I could not save my kidneys despite years of suffering and deprivation was traumatic and disillusioning, but going to the adult renal unit was far worse. It was an unspeakable place of uncaring doctors, hostile nurses and spiteful clerks, many of whom seemed to derive satisfaction from tormenting dying patients. No one (for instance, the doctors) ever stopped the clerks from tormenting us and the patients were too frail and too dependent on their "care" providers to fight back. I have since learned that this is called "lateral violence" or "internal colonization" (Griffin, 2004; Marquard, 1957; Stanley, Martin, Michel, Welton & Nemeth, 2007). When you make the coloniser's laws your own, very bad things happen. Disempowered workers in institutions work out their frustrations on less powerful others, for instance, in hospitals. Generally these groups of oppressed minorities cannot fight back. As a patient you were not human there, but a number to the clerks, a file to the nurses, and a urinary tract to the doctors, and you gradually had all your hope and dignity stripped away from you.

This early part of my story is so much more medicalised in my mind still, I think partly because I still believed in the power of medicine. I believed that if I did as I was told the result would be positive. But it wasn't. And in the awful adult renal unit, where I was forced to spend three years of my life, I had to face the reality that systems are not necessarily designed to make life easier and that one's so-called care-providers do not always have one's best interests at heart.

This strange no man's land in which I found myself was a transitional period for me in terms of learning how to tell my story. In the paediatric unit my mother and I had always re-told the medical story my specialist had told us, about the importance of blood tests, medication and clinic visits, about separating clinic life from the rest of my life. But in the adult renal unit I no

longer had this story. I had been forced to see that this was just a tale doctors told themselves to make sense of my situation and then relayed to me to make me feel better (Marzano, 2009). Sometimes they were right and sometimes they were wrong. They were like the weather bureau: they could make forecasts, but they could not guarantee that their predictions would come true. They also skirted around the issue of organ failure and death (Good et al., 1994; Marzano, 2009). This unspeakable truth haunted me. I tried very hard not to see it and to listen to their official narratives.

I found myself without a story and in chaos (Frank, 1995). I needed to make sense of my life as it had become and so I told myself small stories that involved, for the first time, what I had done about my medical condition. Usually it involved protecting myself against the carelessness, incomprehension or exhaustion of the clinic staff. I related my small victories to my mother and complained to her about my not-so-small failures: the time I showed a doctor that I understood my medical condition so he did not need to patronise me, the time the doctor insisted on prescribing medication I was allergic to, no matter how hard I tried to convince him otherwise.

Life veered between chaos and a terrible order, the one that everyone could see at last – the inevitability of my going into complete kidney failure and dying. It was inescapable. Only two things could save me: dialysis or a transplant. And even this was not to be taken for granted at a state hospital. Resources were scarce and people were turned away from dialysis regularly. My new doctors had decided I should receive a related living donor transplant and had approached my father about donating. He was a medical colleague so they were confident he would agree. They would not listen to me when I told them he would not. Their inability to hear my life story of a highly dysfunctional parent-child relationship nearly cost me my life.

I was not a nephrologist but, unlike them, I knew my family all too well. And I was right. My father never had any intention of donating to me. It took the doctors a very long time to see this, a very long time where I was not put on waiting lists and was not given alternative treatment, such as dialysis. Even after their surprise at his refusal, even after all the evidence to the contrary, they kept insisting that their narrative of our family was the correct one and that mine was not (Garden, 2010). I came to see that despite their assertions about their scientific objectivity (which, in their view, made them omniscient) they were influenced by their own experiences and needs. One had a complex and troubled relationship with his father, another idolised his father, and so on. They needed to believe the parent-child bond was sacred. I had no such illusions. I could not afford them. Their belief in their omniscience prevented them from accommodating views that differed from theirs. This frightened me, because I could see



that they were not all-knowing and their sometimes flawed decisions affected my life, even my very survival.

#### 4.4.3 *The illegitimate narrative*

Narratives are very powerful things. They can dictate one's fate. The doctors' incomprehension of any expertise beyond their own and of any narrative beyond their medical narrative nearly killed me. No matter to whom I tell this part of the story, even now, I am still met by incomprehension. It does not suit the legitimated narrative of organ failure where the sacred family bond always saves a relative dying of organ failure (Cojocar, 2007; Hermans, 2006; various authors in Hutchinson & MacCallum, 2000; Klug & Jackson, 2004); the family would never turn its back on its own. Doctors are meant to be the experts who save you (Cojocar, 2007; Hermans, 2006; various authors in Hutchinson & MacCallum, 2000; Klug & Jackson, 2004; and many, many others), not the people you have to fight to get treatment.

My illegitimate narrative (Clandinin & Connolly, 2000; Nelson, 2001) of my doctors' dangerous incomprehension remains invisible, unheard, unspeakable. My hopelessness about it makes it even more so, because I hide the story now. I wasn't going to tell it here. I have learned not to tell it and yet it hasn't gone away. It is the palimpsest (Derrida, 1998) that shines through all my other stories, the ghost that won't be exorcised. It has affected many of my decisions and probably all of my relationships since then. It is in some of other form in every chapter that follows this one.

Through all the silences in this text, my narrative is still very long. It had to be to allow me to move from one point to another and I retained as much of the length as possible to show my path and to avoid reducing my narrative to bits of text that could be used as examples to illustrate points in an argument. I could try to contain the narrative (more than I already have – you're only seeing snippets of it here), to make it reshape my experiences and identity, to do as Muncey (2005) did. I could show the parts that explained how in control I was of my medications from the age of 9 and how I worked out strategies of coping with my needle phobia. If I wrote those parts instead of what I have shown here, I would be lying about empowerment. As an ill child, I did not have much power or agency. At this point, my narrative for this period explains how I experienced renal disease. Metaphorically my dreams (in the third snapshot) give the most accurate and primal description of how things were. When I saw the nature of my yam dream and returned to my dream diary of the time, I nearly wept. I never had wept about it. I had simply endured it. As a child, it can be difficult to make the leap between understanding obvious grief and loss (how you felt when your beloved grandmother died) and understanding not-so-obvious grief and loss. How do you mourn something you never had, especially when you cannot even name it? Avoiding it is easy enough. You simply

never talk about your fears or compare your narrative with those of others leading different lives.

I have seen in writing this chapter that although the events occurred long ago, understanding them is still a process and remains unfinished and largely unanalysed. I should like this chapter to remain unfinished, messy, bulky, rough, because it performs its part so well. Writing like this and not tidying it up has helped me to understand the nature of growing up with a dread disease.

In a sense my “snapshots” are subtexts to the official medical discourse. I am writing back to the (medical) coloniser (Pratt, 1992). I do not, however think my stories are truly counter-stories in Nelson’s terms (2001), because they don’t undermine the dominant narratives, but co-exist. Perhaps reading them together gives one a more comprehensive story. However, I know that the colonisers will not be reading this. It will be read by people who are interested in qualitative research. It ought to be read by medical doctors, but most are not interested enough in qualitative research. My narrative cannot deconstruct the medical narrative, because that narrative is mostly valid and I rely on its narrators for treatment. For them to treat me, they have to be left to tell their story, because it helps them to make sense of their world.

#### *4.4.4 Recovery and rememberment*

My putting parts of the narrative back together is a type of rememberment, I think, more than a remembrance. To some extent any story is. As storytellers, we behave like Isis reassembling the scattered remains of her dead husband, Osiris, and hoping that in some way he will return to life. However, it is more than this. It is impossible for me to think about the stories that these fragments show without supplementing them and adding to them. It is also impossible for me to add to these stories without evaluating them as narratives that are incomplete. When I do this, I am both thinking *about* stories and thinking *with* stories (Frank, 1995). My stories change as my understanding of them develops and vice versa.

In the myth, Osiris cannot really return to the world of the living, although he is a god. Instead he becomes the King of the Dead and lives (so to speak) in the Underworld. He is a kindly and beneficent king and his kingdom offers new hope for the dead. In his kingdom the dead live again in a different fashion, according to what they deserve. Most people have daily feasts. Now, it seems, there are not only two spaces you can occupy: dead or alive. There is a third one: the Underworld is a place where you can be both dead and alive – or even something else entirely. Sandelowski (1991) describes stories as liminal spaces. In my (Egyptian) conception of storytelling, the Underworld is not limbo. It is another place entirely. It is not Pratt’s (1992) borderland. It is not a subtext or a counter-story (Nelson, 2001). Instead, the

Underworld is another realm. Stories are another realm too. I have found that they can provide a story teller with a new environment in which to explore an experience. They are never the experience itself brought back to life.

Sandelowski (1991) described stories as liminal because she saw them as a way of getting from one place to another in terms of identity or understanding. I agree with her idea that stories are part of an experience of change and can help one to conceptualise it, but I find stories are more than that. They are themselves dynamic and changeable like waves against a sea shore, with the tide line always changing. Understanding events that occurred long ago is a process. I am coming to suspect it is a process that cannot end, but must stop in an interesting place.

This isn't the deconstruction I was hoping for, I am sad to say. A narrative that never really existed before cannot be deconstructed. It is a story of silence. It does, however, contain some pleasing, postmodern ironies: the disappearance of my story possibly prevented me from experiencing disappearance (Leder, 1990). In finally telling the story I am possibly too far away from the events to experience disappearance now and feel only grief and dismay. I made some type of sense of my story, but remained perturbed by it and somehow unsatisfied by it. What is still missing? Where did I go when my story disappeared and did I ever really come back?

If nothing else, it is clear to me now that because chronic kidney failure takes years, this will affect the type of narrative you are able to tell. The length of my narrative and its scale, years of my life, is daunting. Chapter 4 feels at this point like the *Bloomsday* (Joyce, 1986) of renal literature. When chronic kidney failure happens during childhood and adolescence, the changes that you experience are so gradual and mixed in with so many other changes that keeping track of one's medical condition and experience of illness can be difficult.

Illness is no more static than health, and even within illness, periods of relative health can exist (Thorne et al., 2002). One of the challenges ESRD sufferers face is that their condition is not likely to remain stable (Stein & Wild, 2002; Walser, 2004). These days the hope is that we will die of other causes and that seems likely with medical advances. However, ESRD is always fatal if untreated and sometimes fatal with treatment. It is as fatal as some forms of cancer. Our condition remains terminal and the only therapies available, transplantation or dialysis, are not cures. Stories, like poems, are only ever a temporary solution to chaos and uncertainty (Frost, 1973). Can you really construct a healing narrative out of a condition that is terminal and changeable? I have not been able to, at this stage. Other parts of my story could be different.

I wanted to keep this part of the story tidy, separating the lights from the darks, the academic from the personal and from the medical. In practice it could not work out so tidily and still be more or less true to my understanding of the events. And so my story is not black and white, but multi-coloured and multi-textured. It is not at all as I intended and I have to console myself: while my rememberment cannot give me back the story I should have had as a chronically ill child, perhaps it can create a type of story against which other children can tell their own so they are not swallowed up in a medical narrative. In discussing it I have to resist my urge to order it and to add to it. Now we have to backtrack to the future. I wrote the next chapter before I wrote any other chapter. And I did so for very specific reasons.

The whole of Chapter 4 is the context for much of what follows. It is always there, like a ghost, or a Derridean palimpsest, visible through the other texts. I see that now. In telling parts of it for the first time here, I can see that I needed to tell it. I needed to be heard, but I also needed to conceptualise it, because I never had. Like Rosaldo (1989), when I finally started to write about it in my journal something happened. Rosaldo had been studying how Ilongot people experienced grief and felt he had a good intellectual understanding of it. However, none of this helped him understand his own grief after the accidental death of his wife. At first it silenced him and a year later, when he began to write about it, he could not stop. It was like a type of frenzy or possession.

I too had lived through an experience that I found impossible to articulate, partly because it was huge and painful, but partly because my narrative was at odds with the formally accepted, legitimate narratives I had encountered. When I managed to start writing about it, tidal waves of my own narrative buffeted me. My littoral zone changed completely. My shoreline and boundaries are not the same. Whether this change is permanent or temporary only time will tell. As things are now, I find myself dismayed by what I have seen and not seen. And I find myself experiencing the same sort of helplessness that I did as a child.

## **CHAPTER 5: CROSSING OVER - THE DISCURSIVE (THIRD) SPACE OF DIALYSIS**

### **5.1 Introduction**

In this chapter I do two things. I tell the story of my own experience of peritoneal dialysis (an abdominal catheter system that cleans toxins out of one's body), taking into account that I subsequently underwent a successful transplant and that twenty years have passed since I needed dialysis. I also use my story to structure the chapter's argument by comparing and contrasting my experiences with those of others to demonstrate the complexity of telling this type of story. One of the factors contributing to the complexity of the story of dialysis is the length of time (many months if not years) that most people spend on dialysis. As my story shows, one type of narrative can easily become another type, even if one's stay is relatively short as mine was.

I wanted to tell my own story, but also to discover if a "dialysis narrative" exists as a cultural trope and to what extent dialysis reflects current social concerns. Is the expert's version of dialysis the dominant form, or is it subverted by the narratives of lay people? And who is ultimately the expert on the dialysis experience?

For the first part of the chapter I discuss how narrative functions and what dialysis is. My story continues in narrative form after this. I have divided this part of my story into eight phases to show when and how things changed. After this I discuss tensions and analyse emergent themes. My own narrative, although more detailed than some, is incomplete, so I will also discuss certain themes I did not include in my own narrative and what these hiatuses indicate.

Remember, I have already started my story about dialysis. It began the moment you started reading this chapter. This frame is part of the story. Remember, too, that the story continues even in the academic parts of my writing, because the way I reason about it as an academic is as much part of how I understand it as writing the personal narrative is.

### **5.2 Dialysis and the possibility of a new narrative**

Safety was the reason I wanted to write about dialysis in the first place. Many people would not view dialysis as safe, I suppose, on reflection. They tend to see it as a horrible medical invasion and experience it as a loss of control and a damaging of identity (Cojocaru, 2007; Russ et al., 2005). My experience was different. For the first time in years, I experienced

feeling safe and looked after when I came up to the dialysis unit. My trust in medicine and doctors had been undermined in the adult renal unit and had filled me with a howling sense of rage and injustice. We were treated as numbers and, worse, we were treated as hopeless cases. The doctors could not cure our disease, so we ceased to matter to them (or so I experienced it). ESRD cannot be reversed, so the adult renal unit was merely a holding pen for untreatables. It was a relief for me to get onto dialysis at all after a long wait and a redemptive exercise to be able to experience being treated as a human being in the dialysis unit. I may have had a number there, but the staff never used it. In the dialysis unit the staff looked you in the eye before looking at your chart and they spoke to you or even with you, instead of at you. It was as if you had returned to the living. This could have accounted for my positive outlook on the matter.

I noticed, however, that my rosy view of dialysis is not shared by many writers and researchers. Dialysis is composed, constructed and deconstructed in different ways through narratives written by people who have been on it and by people who have not. It is a slippery and complex subject that has caused researchers to realise that observing the lives of others living with renal failure can result in oversimplifications and that “a more ecological and ‘situated’ portrait of life with renal disease” is called for (Faber et al., 2003, p. 144). In addition to this, there is an implicit debate in the literature related to quality of life on dialysis concerning whether the patient or the care provider should evaluate their own quality of life (Martin-McDonald, 2003/4). To the onlooker, life on dialysis can seem no life at all, but a person living on dialysis could experience it differently. I myself spent eleven months on peritoneal dialysis, so I decided to write this chapter to show what it meant to me.

No narrative is ever complete.

All writers, each time they write, work through the tensions and compose a text that can always be otherwise, always be improved, a text that is inevitably only a step, a kind of placeholder, from which still other inquiries with still more field texts may be imagined and pursued. (Clandinin & Connolly, 2000, p. 157)

No story can tell everything, however much its narrator may wish to tell the whole truth. For one thing, there simply is no time to reproduce events that may have taken years. For another, because narratives are a way of ordering and structuring meaning, the narrator is going to emphasise certain things and de-emphasise others in order to retain a narrative thread. While my story will, like Foucault's (1975/1991) interpretation of commentary, make certain things visible, it will also render other things invisible, legitimate some power structures and render illegitimate others, allow some voices and disallow others.

In a certain sense narratives are extended snapshots (Muncey, 2005). Not only do they concern a limited number of related events within a limited timeframe in the narrator's past, but when the story is told, it is also narrated within a limited timeframe and at a specific point in the narrator's present life. This all affects the meaning. In my own case, for instance, I was never able to tell the story of my illness and transplant in any way that was meaningful to me until many years had elapsed. When I tell it now, I am 20 years older than when my illness reached a crisis point. I have a completely different perspective on it now. No doubt in 20 years' time my view will be different again.

In addition to this, illnesses have their own favoured narratives. Kidney failure is no exception. The different stages of kidney disease (CKD, the news of ESRD, living with ESRD, dialysis and transplantation) each have their own narratives and these vary depending on who is ultimately telling them: the patient (Cojocar, 2008; Etherington, 1991), the doctor (Kirmayer, 1992; Zaner, 2004) or the social scientist (Crowley-Matoka, 2005; Faber et al., 2003). Moreover, a clear distinction can be seen between narratives of people who have had successful transplants and those who have not. For many patients dialysis is a passing phase. For some it is permanent. The narrative one would write depends greatly on whether dialysis is part of the journey or the destination.

In telling my own fractured narrative in a certain way I create a story that mirrors some of the complexity of the experience. I also blur the distinction between researcher and narrator, for I am both. I do not wish my narrative to become data in my own writing. There are three spaces in which narrative plays a highly visible role. My intention is that these parts should also change the way in which you read the other parts of my dissertation. Narrative is read differently from linear academic writing. It requires a lot of going back on many levels.

### **5.3 The role of dialysis in treating kidney disease**

Kidneys are vital organs. If they do not work, you die. These days, organ transplants are fairly successful and kidney transplants are the most successful solid organ transplant (Helman, 2007). Dialysis is generally seen by the medical community as a way of prolonging life or chronic life support, rather than a treatment and certainly not a cure (Fox & Swazey, 1992; Joralemon & Fujinaga, 1996; Russ et al., 2005; White & Grenyer, 1999). Some researchers take exception to this, even calling it "postponing death" (Fox & Swazey, 1992; Russ et al., 2005). I notice that none of them seem to have needed their own lives prolonged. This is possibly a coincidence. One rather important idea seems to be missing in all this philosophy: our fear of death – or, to put it in more positive terms, our will to live.



Dialysis is on the threshold of life and on the threshold of death. So why do people go onto dialysis when there is transplantation? One compelling reason is that there are far more people in kidney failure than there are people donating kidneys (Fox & Swazey, 1992). Another reason is that not everyone can have a transplant. A third is that transplants do not always work.

There are two types of dialysis: haemodialysis (or the “kidney machine”) and peritoneal dialysis. Haemodialysis is better known because the vast majority of dialysis patients are on haemodialysis. Peritoneal dialysis (the sort I was on) is not as efficient as haemodialysis, but it is not as violent, although it comes with attendant risks of systemic infection.

Dialysis requires a great deal of organisation from the person on it and their family. It becomes an unavoidable part of everyday life. This could be why it might also become a symbol for an illness. In other words, kidney failure when chronic is a slow decline which can for a long time be imperceptible. When acute, it happens so suddenly that one has no chance to adjust. Dialysis can come to represent the illness and its losses because it is a concrete artefact. It is easy to see and its effects are easy to feel. But dialysis is not the illness. It is the treatment – or rather, it is the levee against the rising river.

Possibly because dialysis is to an extent outside of one, it can be safely seen as a symbol for painful things, sometimes unbearably painful things that are inside one. It can come to represent losses that predate it, such as the loss of one’s health, one’s physical mobility, one’s freedom, one’s relationships, one’s kidneys. It is the result of these things, not the cause of them, but in one’s mind it can become the reason things went wrong, when there is no reason.

Dialysis is a perplexing thing. It prevents or postpones death, but it is not a cure. It has been described as “not-quite-life” (Russ et al., 2005, p. 297). People suffer on dialysis and this can be disturbing to see (Faber et al., 2003; Fox & Swazey, 1992). Often observers of this suffering resort to an “appeal to Nature” argument – it is “unnatural” to prolong life through “artificial means” and this causes people to suffer more than if they had died (Fox & Swazey, 1992; Russ et al., 2005).

I suspect that there is confusion about the status of dialysis. For instance, Helman refers to dialysis as “life enhancement” as opposed to other therapies that are described as “life saving” (2007, p. 12). Dialysis is essentially “chronic life-support” (Russ et al., 2005, p. 297), although patients do not need to be on it continuously, as they would on a ventilator. You can live when not connected to the kidney machine, but only for short periods. With peritoneal dialysis you are constantly connected, but it is not as startlingly visible. Your own body continues to dialyse

for you, but now your peritoneum performs some of your kidneys' roles. You are likely to be well enough to organise your own bag changes as I was or to hold down a job, study or look after your children. In other words, you can function in society, be productive and not need to be in hospital all the time.

It is precisely the intermittent nature of dialysis that renders it so perplexing. If one is only temporarily connected to dialysis (in the case of haemodialysis, at least), then one is only temporarily on life-support or even temporarily a "cyborg" (Faber et al., 2003; Helman, 2007). Helman talks of new bodies emerging in the twentieth century – composite bodies that contain parts from other people's bodies via transplantation, cyborg bodies that are part human, part machine, and virtual bodies that exist via electronic media (2007). Although this list includes dialysis, I maintain it does not truly accommodate bodies that undergo dialysis. I would also argue that this still-medicalised view of the body does not truly address the idea of the self, which even in today's scientifically influenced discourse, seems to extend beyond the body.

However, technology does not annihilate the self, but allows it to alter by stretching one's symbolic skin (Helman, 2007). The self adapts to its circumstances. As traumatic as dialysis can be, patients usually realise that it is life saving and adapt themselves and their lives to it (Martin-McDonald 2003/4). Our symbolic skins are, it seems, surprisingly flexible.

Dialysis is such an intimate thing and, paradoxically, it is simultaneously the opposite of intimate. Your body, your space, your being, are claimed by medicine and connected to an inorganic system that will perform the functions of your kidneys, the delicate filtration organs on which your life depends. You develop, or perhaps lose, a symbolic skin. Your boundaries are no longer as they were before.

Something that is meant to happen beneath your skin, unobtrusively and naturally, now happens when you are connected to an external system. You have to set aside time for it and you have to watch it happen. You have to watch very closely, in case things go wrong, and you have to fix them. Sometimes you cannot and then other people have to. People on dialysis can experience this as more loss: the loss of remaining freedom and the loss of privacy.

Your private body becomes a type of public property. Your blood is monitored, your urine, your food and fluid. Everything is measured and charted. You know who you are: a dialysis patient, with certain readings that place you in a category that defines you more or less successful. By the time you need dialysis you will be used to most of the restrictions already. For years before (in my case anyway) you will have monitored your blood, urine, food and fluid. It is one thing to watch someone experiencing dialysis; it is quite another to live through it.

As a life of suffering and restriction, life on dialysis is perhaps more liminal than at any other point in CKD. Dialysis is after all life support and the people on it are in a weird state of being alive through “unnatural” means, existing somehow between life and death. Their illness and dialysis render them invisible. In the case of dialysis, some of the stages of Van Gennep’s (1960) rites of passage are literally reproduced. It literally removes them from society. During the period of removal, many literal purifications are performed, as dialysis removes the toxins from their systems. However, dialysis must be repeated, so the person experiencing it can never really complete the ritual, but must always return again to its beginning.

Dialysis creates a unique discursive space. It is a borderland between three very different kingdoms, ESRD, transplantation and death. For some it is limbo (Fox & Swazey, 1978); for others a waiting room (Russ et al., 2005). It is on the threshold of life and on the threshold of death. Some think it keeps you alive, but stops you from living (Russ et al., 2005). But if you needed dialysis and did not get it, you would not live at all. So what are the alternatives to dialysing?

However, these spatial metaphors do not fully capture the changeable, temporal nature of dialysis and the dynamic nature of the elements in its discursive space. Dialysis takes time. The amount of time it took me was something I never dwelt on. A doctor once told me that no time is ever wasted and I started to understand what he meant when I was on dialysis. Life is just lived. Whether you do what you choose to do or what you have to do. My story, which follows, contains eight phases that go part of the way to exploring that space.

#### **5.4 My story (1): Death is a cowboy**

*In the movies I’d seen, the cowboys always won. Maybe that’s why I identified with the “Indians”. When I went back to university after my peritoneal dialysis line was put in, I felt very strong. Even though I was by conventional standards pretty anaemic, with a haemoglobin of seven, I could walk up stairs – even run up them – a week after the line was put in. I wore my favourite outfit on the first day back at university: a white viscose cowboy shirt with little cacti on the collar and a cowboy and “Indian” chasing each other twice across the yokes, stone-washed jeans and pointy cowboy shoes (I couldn’t find cowboy boots in Johannesburg). The “Indian” on my shirt was ahead of the cowboy (why I’d chosen it); it wasn’t clear if he was winning a race against the cowboy or fleeing from him. I still saw myself more as an “Indian”, but I thought it would be nice to be on the winning side for a change and to be a type of self-appointed cowboy. We had our honours seminar on the sixth floor of the library and I no longer had to wait for the lift. I beat my friends to the seminar room, even with my heavy book bag. One friend said she must be*

*really unfit if I could beat her on dialysis, but she didn't realise that my muscles were building up again, even with the protein loss through my catheter. I was becoming fit, because I could exercise at last after years of not being able to climb stairs. I felt better than I had since I was 15. I was 21.*

## **5.5 My story (2): Dialysis as passing**

*Part I.*

*From 1990 to 1991 I spent 11 months on peritoneal dialysis while waiting for a kidney transplant. Years later, when I started to write my own story of CKD and transplantation, I started with dialysis although it was hardly the beginning or even the pièce de résistance, the transplant. I had written at quite some length about the build up to ESRD, focusing on how my childhood and adolescence had been structured by renal diets and medication, but when it came to the transplant itself and the life afterwards of being well – a phenomenon I had never known – I found myself hesitating. There was something curiously unstructured about that life, something almost chaotic or anarchic. So I focused on how dialysis worked, instead of skimming over it to get to the “good stuff” of organ transplantation.*

*Even 17 years later I remember an amazing amount about how my peritoneal dialysis worked. In those days, when I was on it, we did all our sterile-procedure bag changes manually, four times a day, every day. I estimate I did about 1,336 bag changes. I remember skipping only three. The system was fairly intricate and you could not miss a step. The drain-out took the most time, up to two hours, if you'd left the dialysate in too long (and it was wise to get it all out). The sterile procedure could take 20 minutes to half an hour (providing you made no mistakes). The bag change itself took seconds and the drain-in time took about half an hour.*

*It was not only the repetition of all those bag changes that emblazoned the process on my mind. It was the feeling of comfort and security I had when I was finally allowed to go onto dialysis, when the doctors finally gave up trying to find a related living donor for me and instead started concentrating on keeping me alive. It was also the relative smallness of the dialysis clinic compared with the adult renal unit at the Johannesburg General Hospital. In the dialysis clinic, the nurses remembered your name and smiled when they greeted you. You were not a number anymore – another patient on the long slippery slide to ESRD, from which their expertise could not save you. Kidney failure patients must be depressing to medical staff. In the dialysis clinic no one told you to stop worrying and “get on with your life”. I now realise it was probably because they didn't expect us to have one anymore.*

*Ironically I now felt more alive than I had in years. I remember that time fondly and this is why I started to write about it.*

*It was also the only time in my entire, life-long medical history that I felt I personally had any vestige of control over my condition. I always carried out my own bag changes. Some patients preferred to have their parents or spouses do it for them. Not me. I controlled every second of it and I loved it. I had never felt such agency in my life.*

## *Part II.*

*For some people the actual event of going onto dialysis is traumatic. I remember little of it except that I was really glad I'd made it and determined I'd learn the sterile procedure in record time, just because the nurses expected us not to be able to do it properly. I do remember a sister from the haemo ward telling me that the doctors might try to make a shunt for haemodialysis in my arm at the same time they put in my abdominal catheter line and that I must tell them not to. Apparently this would be a type of back-up in case peritoneal dialysis didn't work. The doctors seemed not to feel confident about peritoneal dialysis, but I had chosen it because it meant I didn't have to have needles stuck in my arm several times a week.*

*People often complain about the amount of time dialysis takes and how disruptive it is to their day-to-day lives. I did have to adjust my schedule to fit my dialysis routine, but it seemed a small price to pay for feeling strong. Before dialysis I wasn't able to do much anyway, because I was too frail. Perhaps I would have felt differently had I been a parent with children to look after or an employee with a job to keep. Perhaps I would have felt annoyed, had I not been so used to waiting. I had been waiting for years: waiting in clinics, waiting in medicine queues, waiting to feel better. Only after transplant did I really see how ill I had been or for how long. I had never really felt well growing up and had felt really ill since the age of 12. Dialysis came as a pleasant relief.*

*From November 1990 to May 1991, I exercised on my exercise bike, did muscle strengthening sit-ups and hared about campus, as I had never been able to do as an undergraduate. I no longer had to plan my schedule as I travelled into university on the bus, making sure that I wouldn't overdo it and would never double back (no unnecessary trips when you're in ESRD). My head was marvellously clear and I found my studies so much easier. In 1989 I was cursing my laziness for only being able to do half an hour's work a week on my third-year subjects. By 1990 I had been starting to wonder if I was stupid too. I was only taking one first-year subject by that stage and just scraping by. Now,*

*on dialysis, my marks had shot up to firsts. Even my complexion had a faint pinkness to it, despite my lamentable haemoglobin levels. I weaned myself off antihypertensives. It was the first time since I was 9 that I hadn't taken any. Twelve years is a long time when you're 21. Life on dialysis seemed like the dawn of a new era.*

### *Part III.*

*I was the perfect dialysis patient. I never skipped a bag change (other than the three that could not be helped). I was scrupulously hygiene-conscious, to the point of being obsessive. I wore cotton vests purchased at the boys' department at the school-uniform outfitters near our house, so that my catheter's exit site could breathe. I washed my hands at every opportunity with the medicated soap my doctor recommended (and still do). I always showered (and have never fully embraced bathing again). I never put my feet on the bed unless I'd taken off my shoes first. I followed the sterilisation routine to the letter and always cleaned out my exit site, no matter how unpleasant it was. I kept religiously to my exercise routine (I liked the novelty of climbing stairs) and diet (and charted everything for my doctor and physiotherapist to see). I always came to clinic.*

*Above all, I never allowed myself the luxury of slouching. I looked at the patients around me and thought, "I am not like you. I am different. Dialysis is going to work for me and I am really, really glad I am on it." I made sure I was always dressed properly when I came to clinic, even in the beginning after the catheter was put in. I was not going to lie on a hospital bed, vulnerable in my pyjamas, being scrutinized by doctors in suits. I was not going to lie staring into space. As I saw it, if I had to be in the clinic for a certain amount of time, I would use it to read for my degree, write letters and gather information. I would always be chipper, even if I didn't feel chipper, because no one expected it. Dialysis patients are meant to be hapless, helpless, and hopeless. I would be the opposite. No peritonitis for me!*

### *Part IV.*

*Sometimes, as I drained my bag for my monthly sample and waited for the doctors, I would leave the unit where our clinic was held and stroll over to the haemodialysis ward, carrying my dialysis bag in a plastic receptacle, specially made for that purpose. It was a two-litre plastic bottle, with a handle for me to carry it with, and its side cut open to accommodate the draining bag. This prevented the bag and its connectors from being anywhere near the dirty floor. I would go to cheer up the haemo patients and their nurses. We'd drink milky,*



*lukewarm tea from thick mugs and they'd share their toast and marmite<sup>7</sup> with me. We'd talk about What We Were Going to do After Clinic (sleep, eat forbidden food, watch our favourite TV shows or go to the movies, spend time with family).*

*Sometimes they'd tell me what they would have been doing had they not gone into ESRD and onto dialysis. They would have studied, gone to parties, drunk alcohol with their buddies, have had a glamorous job. Some would have got married. But dialysis ruined all that. Their fiancés left them; their bosses overlooked them for promotion or even fired them; their buddies found other buddies who could drink and stay up late. They had to drop out of university, because they couldn't do field work that involved travelling to collect data or work in on-the-job training programmes and were too tired to hit the books. People who hadn't been there just didn't understand. I nodded sagely, even though I was chalking up my second degree. Of course I didn't have to go on excursions to collect data or do study-related jobs. I suggested they maybe choose a degree that didn't involve field work, but they said they couldn't. They could not have been ill for very long, because they expected other things from life than waiting and monitoring their conditions. I did not. I wished for them sometimes, but did not seriously expect them.*

*I did not examine this at the time, but, instead, ate my toast and marmite, which I had not been allowed before dialysis, licked my fingers clean and made a mental note to wash them with medicated soap back at my unit.*

#### *Part V.*

*Sometimes we'd talk about a much bigger and more compelling subject: What We Were Going to do After Transplant. But we had to be careful about that for two reasons. Firstly, of course, no one knew when the mystic event would occur. Once you're on dialysis, it's pretty much because you haven't been able to have a transplant before you became too ill to live without life support.*

*Secondly, some of us weren't candidates for transplant. People who couldn't have a transplant faced a lifetime (however long or short that would be) of continual dialysis with no chance of relief. Those of us who had a chance of getting a transplant viewed those of us who didn't with a mixture of awe and respect, seasoned lightly with pity and horror. These patients were like prisoners serving a life sentence, while we were like prisoners who had to serve a certain amount of time, but who might get out early on good behaviour. The nurses would warn us who the patients were who didn't have a chance and, if they*

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<sup>7</sup> Marmite is a dark brown, salty spread made from yeast extract.



were dialysing when we were there, we'd edit our conversation for too much jubilation and limit the amount of time we'd spend on the inevitable topic of transplantation. Those of us who had a chance would be reminded, looking at our heroic peers, how our lives might be if we weren't careful and would leave the clinic with a fresh commitment to making dialysis carry us to transplant. So many things could stop you from having a transplant. However much we admired the stoicism of our non-transplantable peers, we didn't want to end up like them.

I would leave the clinic each month, feeling renewed and thanking my lucky stars that things were working so well for me. I'd have committed my test results to memory, to share the good news with my mother when she picked me up to take me home and I would tell her who had developed peritonitis (not me) and who was no longer at clinic.

When I was 20, my greatest wish was to live to be 21. I wanted to see spring again. I had always been more of an autumn-loving person, but, when I was dying, I developed an overwhelming urge to see spring, to the extent that I wanted to paint flowers to capture their beauty and fell in love with Georgia O'Keefe. I wanted to see things being born, budding, bursting with potential, not running down, decaying or dying. Now that I was 21 and on dialysis, I realised I could dare to think of other wishes. It was quite a shock getting my wishes to see spring again and to get onto dialysis before it was too late. It took me a while to think of new wishes. I settled rather meekly for finishing my honours degree and maybe even getting a first. I felt sure I'd get a kidney and that my transplant would be successful, but I wondered what on earth I'd do with the rest of my life. I decided to cross that bridge when I came to it.

#### Part VI.

When or if. If you are waiting for a non-related cadaveric donor, you can never be sure when your kidney will come up. Some of those people who disappeared from clinic did not receive transplants nor did they recover. No one recovers from ESRD. Once your kidneys are gone, they're gone. And you can't live without them. Despite my persistent optimism I could not help but notice that patients died regularly. Fortunately I never had to see that happen, as a friend on haemo did, but, in some ways, not seeing it was worse. I would notice their absence and clinic would go on without them. Looking for them would do no good. They were nowhere to be found. Their loss saturated the passage ways and their unsaid names rang in the wards. After a while I didn't ask where people were if I hadn't seen them at clinic, because the nurses' responses were so matter-of-fact ("Oh, he died.").

*I agreed to play the game whose rules were unspoken: Don't look and don't tell. Pretend it's all right. Focus on the living.*

*And yet that cold current flowed beneath us as we ate our toast and marmite and drank our tea. It was like that feeling you get in airplanes sometimes: we are very high in the air travelling very fast in a tiny tin can. This should not be working! If anything goes wrong we haven't a hope in hell! We are millimetres from total annihilation! Live life to the fullest while you can, I thought to myself, washing my hands.*

#### *Part VII.*

*I didn't get peritonitis, but I did get bronchitis. That winter I started to struggle and grew weak. I hadn't even had a cold that year, while all my university friends had come down with coughs, spastic colons, shingles, migraines and many other stress-related disorders. I was starting to feel invincible. But my hubris caught up with me. It started as a catarrh. It quickly travelled to my lungs. I don't remember how long I was ill, but I came to wonder if I would ever be able to breathe unimpeded again. I produced an impressive amount of yellow phlegm. It was the only way in which I was productive at that time. I was grateful for the mid-year break, so I didn't miss classes, but I fretted about getting behind in my reading.*

*My doctor told me it was a bug that was going round, but that I was as sick as I was because I was already ill. At first I did not understand he meant I was ill enough to be on dialysis. I had come to see dialysis as a stage in recovery, because I felt so much better on it. I had to take a lot of antibiotics and my blood pressure had to be monitored constantly. I spent a lot of late June and early July in bed. I reasoned this was good, because the weather was chilly and our house unheated. My mother was very worried. This irritated me. It was only bronchitis, which I got almost every winter since I was 15. However something had changed.*

*And when a kidney did come up for me, I was too sick to get it. I could not have the transplant while full of infection, because my heart might not be able to cope with the anaesthetic and the immunosuppressants would ensure I died a quick death. Any infection could become lethal with a compromised immune system. Even tooth cavities had to be dealt with before transplant. I had waited six months on dialysis and much, much longer before that for that kidney.*

*I missed the kidney, but I didn't miss my bag changes. I had learned early on that I felt much worse if I didn't dialyse enough. No amount of tiredness was an excuse to avoid*

*changing my bags. I was always ill – “sick notes” didn’t count where I was. I went to classes if I felt lousy or less lousy. Likewise I changed my bag despite how I was feeling.*

*My biggest challenge when ill with bronchitis was keeping my bag changes sterile. Keeping things sterile is generally the biggest challenge with peritoneal dialysis. So I soldiered on, being careful not to cough or sneeze over my changing table. If I had a coughing paroxysm while in the middle of the procedure, I’d have to start all over again. If it came upon me at that delicate point while I was disconnecting the connector, I had to work really fast, trying to see through streaming eyes, while my body spasmed and I held my breath until everything was safely joined up again.*

*I stopped coughing and my chest eventually cleared (it took about eight weeks), but I could not get onto my feet again. I had not been able to exercise while I was ill (or more ill, according to my doctor) and, at first, I reasoned that I had simply lost muscle tone. I had to fight to maintain it, because of all the protein I lost through my kidneys and the dialysis system. Sometimes the protein would be visible in the catheter bag, like long strands of egg white in Chinese soup. Suddenly I was too tired to cycle much, always breathless. Stairs were a problem to me again. I said to my mother and my friends that I was unfit and that I must get back to my exercise routine, but inside I knew what was wrong. I was wondering once again if I would see another spring.*

*Your body knows when it’s dying. Although I had overcome the bronchitis, I knew in my heart that I would not survive another winter. I had lost some vital spark, coughed it out of me perhaps. I wasn’t going to live as long as next winter. I did not tell my mother. I thought I should, but I did not want to upset her. Instead I hoped that another kidney would come up for me before the next winter and that I’d be well enough to get it. What was another year’s wait when you were alive?*

*I had been afraid of death for as long as I could remember. When I was small enough to be in nappies I had a dread of not being able to breathe. I had a morbid fascination with the lengths of people’s lives and anything related to death and decay, be it burial rites or biological processes. I was surprised to discover that knowing you are dying is not that frightening. It is a fact, like knowing you are hungry or knowing you are tired. Death is just something that happens. At a certain point the body knows that and so does your mind.*

*I did not want to die, however. I had had a taste of living and I liked it. My mind wanted to fight death with everything I had, while my body wanted to give in to it, because it was in the natural chain of events and I was spent. It seemed so unfair suddenly. I hadn’t thought*

*much about the future, because I was unsure what to do with one, but now I tried to scramble for a plan – a focus – something to live for. There were things I hadn't done, many, many things. I wanted to turn 23, even 30! Imagine what I could do with nine more years! I couldn't even begin to think. I started bargaining with God again, hoping He wouldn't notice I didn't have a plan.*

*I suspected that my body would win over my mind, because nature always does. No one lives forever and, in the general scheme of things, the difference between a single human life being 22 years or 62 is infinitesimal. I had studied ancient history, where we dealt in hundreds, if not thousands, of years as a matter of routine. I knew that to the universe, thousands of years are as the blink of an eye. No one life matters that much in the bigger picture and when you're dead, nothing matters at all. You disappear and people stop talking about you.*

*Before dialysis I used to go to sleep at night wondering whether I'd wake up in the morning. The tiredness I felt then was as terrible as death. I had become used to living without it, although still grateful for its absence. The tiredness I felt now was not the same, but I knew something in my body had changed qualitatively and permanently. It was as if I had taken a fork in the road. It was the road less travelled for young adults, but the road we all take eventually. I remember feeling really sorry I would not see purple irises or jacaranda flowers any longer and wondering why I didn't have any more lofty ideals than that.*

*In my defence I was also sorry that my mother and my friends were going to be left to bear the burden of grief. I wondered if I should write them a letter explaining that it wasn't so terrible really, but felt it would be bad luck to do so, an acknowledgement that I was going to die. I didn't write the letter, but I tried to slip some appreciative comments into my conversations with them. I hoped they'd notice. Then I hoped they wouldn't. I kept changing my bags.*

#### *Part VIII.*

*I had fallen ill in June. By September I was starting to feel a little stronger and was getting back to my exercise routine. I hoped my enforced rest had not spoiled the progress I had made in developing my cardiovascular system for anaesthetic. I tried as best I could to make sure my lungs were clear, with no potential septic foci. Spring came again. In the southern hemisphere spring starts in September. I saw the flowering cherry blossoms on campus and wished I could breathe them into my lungs and take them with me when I*

*died. I kept on waiting. The jacarandas burst into flower. The coldness of winter that had leached into my bones gradually began to dissipate.*

*And so I was fairly well when I got the call in early October – well enough to get my kidney after all, well enough to see spring again, many springs, well enough to fall in love with autumn again, although never quite as deeply as before.*

## **5.6 Discussion**

### *5.6.1 Reading my own narrative about dialysis*

When I set out to write my own story, I felt fairly confident about what I would find. My own experience of dialysis, from what I remembered, was different from those I had read. Dialysis has been constructed in negative ways (Cojocaru, 2008; Faber et al., 2003; Fox & Swazey, 1992). I wanted to avoid doing this, because my experience overall was that dialysis saved my life and allowed me to be well enough to have a transplant (Parts III and VIII). This difference between my experience and those of others fascinated me.

I believed that once I had written my narrative, it too would show that my experience was at least different, if not more accurate, than the narratives I had read. However, as my narrative progressed, I noticed that it had a rather changeable nature. At times I became alarmed to see that my narrative reproduced some of the stories I had read (Parts V, VI and VII). For instance, dialysis is meant to be a sad story about the tragic waste of human potential and a grisly reminder of imminent death (Fox & Swazey, 1992). Indeed, I could see this trend in my own story (Parts V, VI and VII).

On closer examination, I was relieved to see that more was happening in my narrative than mere reproduction. I told the story as I remembered it and as it made sense to me, many years after the event. My persistent impression was that my story was qualitatively different from the others I had read. I wondered if this difference was a result of methodology. After all, I was writing a detailed story of my own experiences, while often the other stories were shorter stories in collections of other narratives compiled for research purposes by those who had not themselves been on dialysis (Faber et al., 2003; Kirmayer, 1992; Martin-McDonald, 2003/4; Russ et al., 2005; Zaner, 2004) or, if told by the person who had been on it, it would be a smaller part of a larger narrative and its theme was usually to show how much better transplantation was (Cojocaru, 2007; Etherington, 1991). I secretly hoped that my story was different because it was mine.

I found the realisation that my own personal narrative might already have been narrated curiously disconcerting and this was not mere vanity. I would like my experiences to be my own – to be authentic and particular to me. Part of the purpose of my research is to inform others; part of it is to inform myself. Because the research is about my life and I come from a Western, individualist tradition, I have a personal stake in it. My identity is composed, in part, of my experiences and my culture. They make me, to an extent, who I am.

There was more to my perturbation. As a person who has spent a life in various types and degrees of medical care, whose very existence for a while was defined by it, I find the idea of being assimilated into a general discourse alarming. In the wards and in most of the clinics I was simply another patient who presented certain symptoms to be studied and treated. I was not a person in the fullest sense and my interactions with many of the staff were not as one human being to another, but as a case to a specialist, or a set of symptoms to a care provider – or even a file number to a system. My life and circumstances were subordinated to institutions and discourses that were much more valued than me (Goffman, 1963/1990).

One of my personal goals was to demonstrate that despite everything I had been through, including the medical system, I was not just another patient. I did not have to fit in with what the doctors expected. They were not always right and their melancholy prognostications did not always come true. I did not have to be sick and weak just because my kidneys had failed and I was on life support. Life support did not mean I could not have an independent life. In short, I was reconstructing myself through my writing, healing a damaged identity (Bury, 1982; Frank, 1995), an identity damaged by medical perceptions rather than by physical illness. My writing was an act of self-assertion and a way of reclaiming my life of that period. I remembered it as being full, not empty. I remembered being part of things for once, instead of looking on from the outskirts. I could not (literally was not able to), at first, remember being scared, as I had been for so long in ESRD. In fact, when I had written my eight-phase narrative and was writing my discussion for the first time, I stated quite adamantly that I had never been afraid on dialysis, despite having just written in my narrative that I was.

But in constructing a narrative that “beats” the system, I seemed to be constructing a narrative of triumphing over adversity, which is another standard illness narrative. Was I merely constructing another triumphalist narrative of free will and persistence defeating circumstances? I decided to return to my narrative for another look.

### *5.6.2 The narrative revisited*

The first thing I realised is that my story above is a very brief and sketchy outline of eleven months of my life. A more comprehensive narrative would take far too long to relate.

Furthermore, I wrote it as I remembered it 17 years later. After I wrote it and started writing the more academic part of my chapter I was struck by what I had left out. When I returned to my narrative, I found myself looking not at what I said, but at what I did not say.

For one thing, I did not describe what my bag system actually looked like and consisted of. Perhaps I did not describe the system in the story because I am myself so familiar with it. I have found that when I write about my illness and treatment I tend to write about the things that perplex me, so my narrative tends to be a “hard-working” narrative (Jordens et al., 2001, p. 1227). This sort of narrative helps a person reorder their life, reflect on and interpret events. In Frank’s terms, this sort of narrative can help one to reconstitute one’s identity (Frank, 2007). This is certainly partly true of my narrative, but that truth of my “dialysis identity”, who I saw myself as on dialysis, ironically, obscures another truth: what my dialysis system actually was. It seems these two truths cannot exist together.

In an early draft of my narrative, I had written about the catheter system, ironically because it was a safe, contained, impersonal, medical topic, but even there my description was not very detailed and I had to remind myself more than once to put it in. My eventual explanation of how it worked took quite a long time to write. Writing it was hard work. It took much memory wracking. It also took a surprising amount of emotional energy.

Years after coming off dialysis I was surprised to learn that I had done well over a thousand sterile bag changes. I had never computed this while on dialysis. I had simply gone on from day to day, changing my catheter bags, never thinking about it. When I started writing about the procedure I was surprised to find how intricate and laborious it was. I do not remember it that way. Looking back on the process was fascinating. I had recently seen a TV programme on dialysis clinics in rural areas. I was taken aback when I realised that I had lived the illness that afflicted these desperate people. That was why I knew the answers to so many of the questions the interviewer asked. I knew, for instance, why they found it difficult to find or keep jobs. I knew why they struggled to do the jobs once they had them. It was not only the rigours of attending clinic, it was also that they were not physically strong. I could hardly believe that I had gone through so much of that. I experienced the same feeling writing about my eleven months on dialysis. It was a type of archaeology, where you uncover a lost civilisation and find it is your own. How had this information come to be buried? I can only conclude I must have buried it myself.

I also left out the importance of the relationships with other patients, doctors and other care providers, especially the nurses. These relationships sustained me and were on the whole very healing in themselves, compared with my less than satisfactory experiences in the three



previous years I spent in the adult renal unit. From the staff and patients in dialysis I received care, support and information which helped me to make my dialysis experience work well for me. So why then did I omit these relationships?

One of the difficulties in telling this story is its complexity. In order to sustain a coherent narrative thread, I needed to limit the number of themes I would include. I wanted to talk about my experience of dialysis, so I focused on me. But of course no human being exists on their own, not even those who are strong and healthy. A modern Western myth is that we can achieve independence as adults and forge our own paths. In reality we are all part of a variety of communities whose members are interdependent. I focused instead on my experience of dialysis, so dialysis (but not its workings) became another thread. Life on dialysis is very ordered. It has to be. Each day's structure is very clear. This gave me a sense of control. This life's routines are also very repetitive, so they are easy to remember. Perhaps my dialysis relationships were more complex than I realised, being themselves, in some senses, life lines. Maybe acknowledging this would undermine my steely story of self-reliance and control.

I should perhaps have mentioned (but did not) why I chose to have peritoneal dialysis, which augmented my feeling of control. I could say I chose peritoneal dialysis because it more closely emulated the function of normal kidneys, allowing dialysis to take place inside my body without a machine, but I would be lying. I chose it because I have always been scared of needles. So, in a sense, I went onto it not by choice and through control, but by default and dread.

I omitted my personal metaphor for dialysis. I saw my dialysis system as my umbilical cord. Even now, the scar that remains where the tube exited my body resembles a tiny navel, which I see as the evidence of my second "birth" or passage into my new life. Sometimes I would think of my cord as the line that connects astronauts to the mother ship – a variant on the theme. I would imagine myself stepping out into space, into an environment that could not possibly sustain me, if it were not for that fragile line that kept me alive – my life line.

My peritoneal dialysis line was inserted into my abdomen, a few inches to the left of my navel. In the early 1990s, when I was on dialysis, the line was left attached after the dialysate was drained into one's abdomen, so one always had a long plastic catheter tube coiling out of one's belly, with a dialysis bag attached. Dialysis has been described as having an "external kidney" (Helman, 2007, p. 33, and others), but I did not see it that way, possibly because in peritoneal dialysis the filtration area is inside the body, only the results are drained out.

Perhaps, had I been on haemodialysis, I would have thought differently. However, I notice that I am not alone in my description of dialysis. A Canadian haemodialysis patient described his dialysis in exactly the same way (Faber et al., 2003, p. 160). The researchers interpreted this only as his experiencing difficulty and restriction. However gruelling and unpleasant it may seem to an outsider, it is quite different if the equipment is saving your life. I do not know for certain what the Canadian patient meant, but my impression is that he felt the cord was his life line, however restrictive.

The metaphor of umbilical cord is loaded with significance. The unborn baby is attached to its mother's womb by the umbilical cord through which it receives all the nutrients it needs and all its waste is removed. Not only does the umbilical cord feed, it also cleans. My dialysis line did exactly both of these things for me. The cord is security and life and, in my metaphor, that is what it symbolises. It is the connection between mother and child – the most powerful relationship of all, and where life begins on so many levels. I was the one performing the bag changes, however. I now wonder, seventeen years later, if that made me the mother as well as the child. Did I give birth to myself on dialysis? Clearly, I see dialysis, not my transplant, as the beginning of my second chance.

Giving birth, umbilical cords – these are very physical things. So why then did I to a large extent occlude my body in my narrative? Dialysis is all about keeping the body alive and interactions with the body. Being on dialysis is overwhelmingly an embodied experience. Maybe writing about it in a detached way many years later allowed me to control the sense of overwhelming physicality. I tend to do that in my life generally. So my body all but disappeared. Ironically that was my experience of medical treatment generally – parts of oneself or even one's whole self tended to be rendered invisible. Treatment is given to a problem or a disease, not to you, a person, with an embodied life. Doctors would talk over you to each other about your condition as you lay in bed, invisible and unrecognised. Sometimes, after clinics (but before going to the dialysis unit), after being examined, poked and prodded, I would leave the hospital diminished and feeling ghostlike. After being scrutinised all day, I could feel myself disappearing.

However, if my narrative represents my experience of my condition and the medical treatment it necessitated, then maybe it functions in a subversive way metaphorically. The "body" of my text is my narrative and that body is protean. It can shift its shape to elude scrutiny or to redirect the reader's gaze. It decides where it wants to go and what it wants to be. It is not content being data. It wants to analyse as well.

There is another thing I never dwelt on: waiting. I had a mantra I used to chant under my breath, except when I was performing my dialysis routine, because I needed to concentrate on that: "Dialysis is not a way of life. But it's better than the alternative." True, dialysis is restrictive, but so is ESRD. At least with dialysis I could climb stairs. I had been too weak to climb stairs since I was 19. I went onto dialysis at 21. I could exercise again. The dialysis unit's physiotherapist gave me an exercise routine that included various types of sit-ups to strengthen my stomach muscles and an exercise bike routine that toned my legs, but also strengthened my cardiovascular system for surgery. I was waiting for a transplant after all (Parts V and VI).

I waited for 11 months. During that time I did four a day sterile bag changes every day, except for the three changes that I missed. I attended clinic at least once a month. I had innumerable blood tests. I cycled hundreds of imaginary miles through imaginary lavender fields in an imaginary Provence (sometimes they were Van Gogh-like cornfields). I felt so strong that I sometimes raced imaginary trains. I watched too many soap operas – we did not have a video machine. I never got peritonitis. It seems unimaginable now.

I think the most difficult aspect of dialysis is the waiting. It is rather like being in an airport waiting lounge, wondering how long your flight has been delayed. No one who is on dialysis is really there permanently. It is a stop gap of unspecified duration. Everyone has another destination in mind: some believe they will recover and that dialysis will save them (it may do if their kidney failure is acute and treated speedily), some hope for a transplant, some stop hoping and wait for death. Some even speed death along, deliberately infecting themselves or eating the wrong things.

I cannot deny that dialysis takes time. The amount of time it took me was another thing I never discussed. On dialysis I started to understand what the doctor had meant when he told me that time is never wasted meant. Life is just lived. Whether you do what you choose to do or what you have to do your life passes at the same rate. Your life is within you, not in the things you do or do not do. Your rituals become meaningful in themselves, by their very performance. They mean because they are. So for me dialysis was process rather than procedure, more journey than arrival, a metaphor for life.

I wanted to live. I had had to fight for my life from an early age and I was not about to give up on it. Dialysis was a means to an end. Another medical procedure to be learned. In fact, I liked it because I felt relatively well on it and it gave me a measure of control over my health care. I did all my dialysis procedures myself. I felt structured and organised, even accomplished,

especially as I did not contract peritonitis, which is the bane of all peritoneal dialysis patients and their doctors.

Remaining “clean” became a point of pride with me. It brought out a competitiveness in me that I didn’t know I had – and also a type of obsession. I would not use any bag that seemed remotely impure. I would return them grimly to the clinic and the nurses would argue with me that the fluid inside the outer casing was just condensation. I would admonish them to run the bag’s contents into their own abdomens if it was so clean. Of course, none of them were on dialysis, but it did seem to give them pause for thought.

Modern medicine and other technologies have rendered the human body’s boundaries porous (Helman, 2007; Swartz & Watermeyer, 2008). On dialysis I came to see how vulnerable I really was to attack from outside. You cannot walk without walking on the ground, where many others have walked. You have to touch door handles that many others have touched, even if only with your elbow. Your hands go repeatedly to your mouth. Your hands are what change your bags.

Although dialysis is often treated in medicine as a type of pit stop between ESRD and an organ transplant, some people never get organs and many have to live for years on dialysis. One cannot really be said to be waiting if it takes years. That then becomes a way of living – an era in one’s life – or, if not living exactly, a type of limbo. Limbo comes from the Latin “limbus” meaning the edge. In the Catholic view of the afterlife, limbo is where the souls of unbaptised babies go and those of upstanding heathens. It can also mean a prison or a place of neglect and oblivion. Liminality comes from the same source, but it means a threshold. I wonder if the palimpsests of the related meanings of imprisonment don’t shine through nonetheless.

### *5.6.3 Liminality or littorality?*

As a treatment dialysis is a trapping of illness, an artefact of it, or a consequence of it, as taking medication is. And just as taking medication can be a gloomy reminder to people that they have crossed over to the “kingdom of the ill” and are using their other, less glamorous, passport (Sontag, 1978, p. 3), so can dialysis. For someone who has had an identity as a well person, this constant reminder that they are not who they once were can be devastating (Martin-McDonald, 2003/4).

However, for one who has not truly had an identity as a well person, dialysis might represent something else or have a different type of effect on their identity. In my case, I can see, as an older person who has now been well or “well” for a number of years, that my existence before

dialysis was already littoral. From my mid-teens I was very ill. By the time I went to university I was debilitated to the extent that I could barely climb stairs at first and then not at all. I slept fourteen hours a day. And yet I had always been just well enough to pass as normal.

So the more typical liminality of dialysis, the idea of dialysis as a space which one passed through from ESRD en route (ideally) to transplantation and health, might not have made such a strong contrast for me with my previous life. Or, alternatively, my littoral condition in ESRD might have become more liminal on dialysis. In ESRD I was simply separate from my (well) peers, in a strange zone, but now I could integrate to an extent. I could never really count myself as well before or during dialysis. Nonetheless going onto dialysis certainly marked the end of an era in my life. I had never been on it before and it meant that I had indeed crossed some sort of boundary. I find it difficult to establish exactly what that boundary was. Possibly it changed the littoral state of ESRD into a retrospectively liminal one.

I think for other people – those few who knew I was on dialysis – it was a clear and unavoidable sign of how serious my condition was. I remember my grandfather sighing about how hard my lot was when he saw me checking my dialysate delivery each month – 120 bags in cartons of six. I felt irritated by this because my lot had been substantially worse before dialysis, but he had managed not to see it, burdening me instead with household tasks.

Until I was on dialysis, the doctors seemed to treat me as if my condition was not all that serious and yet my condition was life threatening and irreversible. Before dialysis they would tell me to lead a normal life, but would not tell me what constituted normal. I was not able to emulate my well peers and my (as I saw it) failure left me poisoned by guilt, shame and self-doubt. In addition I felt emotionally abandoned by my medical team. This trapped me in a state of in-betweenness where I had not been able to close a door on a traumatic experience and so could not proceed. I haunted my past like a ghost, returning always to the scene of my crime, my failure, my disappearance. Only when I went onto dialysis could I see that the crime had been perpetrated *against* me, not *by* me, so long, in fact, that I had become used to that ghostly girl, too used to her to be able to exorcise her. And so my liminality persists in other ways.

From my perspective at the time, however, dialysis marked the beginning of hope, for I firmly believed I would receive a kidney and that my transplant would work. However, one unavoidable fact remains: it also marked a point of no return. No matter what relief dialysis brought to my life, it really was a type of waiting room before transplant. Had I not been able to have a transplant I would have made the most of dialysis, but dialysis was always only a temporary measure before better things.

Nonetheless, I must have known intuitively that many people would see dialysis as a harbinger of disease and death, because I did not tell many people about it. Or perhaps I had fallen into despair in ESRD, knowing that the well would never understand how my life worked. I remember taking great pleasure in passing as “normal”. It was easier to do this on dialysis.

Passing has many meanings: to be accepted as something, to cross over, to attain a standard in an exam (but not honours), to die. A pass can be written permission for something or a narrow passage in a mountain, often the key route to a country. It can mean that you can at last pass yourself off as something you are not: “normal” (Goffman, 1963/1990). Dialysis is all these things. I sometimes think that dialysis is where I learned to pass in Goffman’s sense, where my most persistent liminal stage began, the one which I have never truly left. I belonged in one kingdom, while passing as normal in another more glamorous one (like a pale-skinned person of mixed race in the nineteenth century, or a transvestite, or a vampire).

However, being on dialysis made me feel as if I inhabited a littoral, third space, as if I could transgress boundaries between the healthy and unhealthy, between the living and the dead, because in terms of natural law I should have been dead. In writing this dissertation I blur the boundaries between researcher and researched. I always found it amusing that boundaries are seen as “facts” rather than social constructs and that stepping over them or ignoring them is seen as breaking some type of divine law. Learning where the line is has the same effect on me as “Keep off the grass” signs.

There are (other) advantages to be gained in appearing well (Belkin, 2008). For myself, when I was on dialysis, I felt better than I had in years and could do more. I wanted to make up for lost time and to lay by stores of things done, in case I once more lost the ability to do them. My strength amazed me and others who knew me. It was admirable and it is so much better being admired than being pitied. Finally I could be passable.

However, while one passes on dialysis, one can render oneself even less visible than ill people usually are (Belkin, 2008; Faber et al., 2003). You would not want to be seen as sick, but if you actually are sick and pass yourself off as well, the real you is not seen at all. Also, if you remove yourself – your real self – from daily life and replace it with a false self, who do you become? A ghost? A memory? Do you pretend to be well so that you can exist in a society in which there is no place for the ill? These tensions remain unresolved for me.

#### *5.6.4 Some last thoughts on my narrative*

Process is something you go through, rather than something that is done to you or on you. For this reason dialysis can open up a discursive space in which the person experiencing it is

dynamically positioned. The narrative that results from an awareness of this changeable state should reveal a complex, “hard-working” narrative of the sort found in studies of cancer patients (Jordens et al., 2001).

I am struck not only by the complexity of my dialysis narrative, but its frequent ironies. Perhaps that is one of its hallmarks. There is something ironic about the entire process, something paradoxical, ambiguous, liminal and unstable.

What I had originally hoped for was a narrative that deconstructed other narratives. Instead, what I found was that my narrative changed from one that constructed dialysis as an improved way of life to a more conventional narrative of dialysis as “waiting room”. I found that through it I became a conventional dialysis patient who was keen to have a transplant and put dialysis behind her. That period after bronchitis when I realised my body had started dying (or, possibly, carried on dying after a brief respite) was very frightening and destroyed my sense of safety. I began to feel once again as if my health was beyond my control and that larger forces than me were going to decide my fate. In writing about this I had re-inscribed myself in a conventional role. I was perplexed. I did not feel that this accurately reflected my experience of dialysis and yet I had written it and it was true to what I remembered.

In some ways my narrative matched those I had read. I had hoped to use my narrative to structure my chapter. Its different parts would have been the entry points for analyses of different stories and for their deconstruction. Despite my apparent reproduction of other dialysis narrative forms, I found my story not similar enough to others’, after all, to provide sufficient points of entry to do this. My narrative was supposed to be my argument, the lens through which I would see how things were. I did not want my narrative simply to be another narrative awaiting interpretation. I wanted my narrative to be a type of analytic lens. And now it even had the conventional happy ending/resolution of a triumph over adversity narrative. What now?

But it was not the end. Quite literally. My hopes revived. I realised I had omitted something else: what happened next. No narrative is ever complete. Each is part of a larger story. If you change the size of the slice, you change the narrative composition. A happy ending is neither necessarily happy nor an ending if you say what happened next. A new ending must then be found and even that will not necessarily be the real ending. I felt a perverse thrill of satisfaction realising the conventional happy ending is only ever a temporary state. Just as the happily-ever-after ending in fairytales is itself a fairytale (for the lovers will eventually grow old and die), a person in an illness narrative might emerge triumphant from their catastrophic illness, but one day they too will die. Did this mean that my narrative was tragic? How ironic that I should



have felt a sense of control and optimism on dialysis and then had a successful transplant in a tragic narrative.

No – my narrative seemed curiously unsettled. Could it be that I had not made up my mind about dialysis despite thinking of it all day, every day for eleven months (something else that did not feature in my story) and having the distance of seventeen years? Perhaps dialysis was something slippery and unfixed, despite its rituals, something that defied categorisation. Possibly I was not a sophisticated or articulate enough narrator to do justice to it. Possibly I was torn between artifice and authenticity. Perhaps the narrative of dialysis – my own, at any rate – is an unstable narrative by the very virtue of its being itself.

Or maybe it was that narratives are by nature recursive. A while after drafting this chapter, I presented a poster paper on what I referred to as “the discursive space of dialysis” (Richards, 2009b). In making the poster I inadvertently added to this narrative, because I realised that I had evolved my thinking about dialysis again and that my poster was now part of my narrative too, like a type of dialysis catheter, attached to the body by a slender connection and important to its survival. The recursive and reflexive nature of illness narratives in particular allows the narrator to revisit the past in order to move forward. At some level we construct them to go back to the past and rewrite them, sometimes over and over, as a ritual, as a temporary measure to counteract uncertainty (Frost, 1973). Each time it will be different and yet the same. Each time we will be different and yet return briefly to who we once were, purified and re-membered.

To this day, twenty years later, I still maintain hygiene habits I learned while on dialysis, because it makes me feel safe. I do think this has helped me reduce my contact with bacteria and viruses. I have been, after all, immunosuppressed since transplant. Maybe I am still purifying myself ritualistically for reintegration into society, still on the threshold. Or maybe I need to keep purifying myself so that I can always go back.

A last word on liminality: a limner is one who illuminates a manuscript. The silver on a mirror is known as the limning. It is this that shows the reflection. I would like to think that my narrative could illuminate or at least reflect something for readers as it did for me about the lived experience of dialysis.

I do not want my last word on this subject to be an academic one. Instead I want to include part of the narrative that I did not in my earlier story. I hope that it will add another dimension to this discussion, as I intended by starting my article with another part of my personal

narrative. In life the story came before the analysis and, as in life, I return to the story after the analysis.

## 5.7 Post script: Leaving dialysis

*But of course, that wasn't the end of the story. I don't really remember having my dialysis line put in, but I do remember having it taken out. This is partly because it was removed under local anaesthetic, while it was supposed to have been removed under general anaesthetic. Oddly enough, even though the operation took an hour and a half and I felt every second of it, that is not what lives with me most. To some extent I dealt with the pain and trauma of the procedure by avenging myself on my surgeon and nurse. When I learned 45 minutes into the procedure that we were only half way through and there was no chance of a general anaesthetic or sewing me up and removing the line later, I spent the rest of the operation telling them in immense detail about the complexities of Classical Greek irregular verbs. They were sweating more than I was by the end of it. I'd like to think I'd played a part in that.*

*What I remember most, even though my new kidney was working so well, was the fear of losing my line. Not "of having it removed", but "of losing it". I tried to argue with the doctors that it should just be left in, "in case", after all, it had been sealed off, by a type of "blind" plug and was now just a few inches long. I could tape it to my body quite easily and it was no trouble to me. But nearly four months after transplant, my kidney was clearly settling down for a long stay.*

*What would happen when the line was taken out? I didn't know. I also wondered how I'd manage my time without the ritual of bag changes. Suddenly there seemed a vast, amorphous ocean of time ahead of me and I felt as if I was lost at sea. Nothing was familiar anymore. I felt more dread about losing that little bit of plastic tubing than I had about anything since nearly losing my transplanted kidney a few months before. I wondered if the doctors would let me keep the tube after it was removed. For one thing I wanted to see what it looked like. For another I saw that tube as part of me, a type of extra limb and judging by how hard it was to separate us, we really had become one flesh. But the doctors wouldn't let me keep it. The titanium plugs and connector were expensive and needed to be accounted for. After an hour and a quarter, the doctor dropped them into the kidney bowl with a couple of small clangs and a gasp of relief. And the tube...I never found out what happened to the tube.*

## CHAPTER 6: LIFE AFTER TRANSPLANT - A STRANGE SORT OF LIMINALITY, OR “YOU LOOK VERY WELL FOR A TRANSPLANT”

### 6.1 Introduction

What strikes me about the literature I have read on transplantation is that the vast bulk of it is written by people who have not themselves had transplants (some instances are Baines & Jindal, 2003; Fox & Swazey, 1978, 1992; Lock, 2002; Scheper-Hughes, 2007; Sharp, 2006; Sque et al., 2006). From these writers' perspectives transplantation means certain things. It carries social or ethical significance, but does not often hold (as far as I can discern) subjective or personal value. In research transplantation is usually seen from the outside. It looks different from the inside. I feel sometimes that my own experiences are missing when transplantation is discussed as simply another example of meta-issues in medicine. How does one achieve a balance between accentuating the needs of the individual and the various costs of treatment?

I have lived though having a kidney transplanted into my body and have lived with my “new” kidney (which is two years older than me) for 20 years, and so transplantation carries a very different constellation of meanings for me. I have also found that the meaning transplantation carries for me has changed over the years, partly as a result of my own coming to terms with what happened to me, partly because my transplant remained stable, and partly because I maintain transplantation is a process as well as a procedure. It is the on-going process of transplantation that I discuss in this chapter, not the medical procedure itself.

The quotation that I used in the title of my dissertation and in the heading of this chapter is at the core of one of the post-transplant stories I tell in this chapter. “You look very well for a transplant” illustrates the unhelpfulness of binaries such as well/ill for people living with my condition. It also reveals how a medical narrative can obscure a personal narrative and damage further an already-damaged identity.

Many studies about transplantation are, I have seen, about transplantation as an immediate, short-term solution, essentially a medical procedure that is done to you as a patient, not something in which you participate. There are few longer-term studies because historically not too many transplants have lasted longer than a decade. These days two thirds are expected to make that mark (McCauley, 2004), because of advances in medication that target specific parts of your immune system according to your needs, so it is important for researchers to look

at the long(er)-term experience of transplantation, and to separate the short term from the long term experientially. Life after transplant is the topic of this chapter. For the patient the transplantation experience does not end with surgery; it begins. I could say that 20 years later I am still “having a transplant”. Keeping and sustaining my kidney is an on-going process.

It is difficult to get away from a medical view of transplantation because transplantation is (partly) a medical procedure. But what happens beyond that? Can we – should we – try to get away from a medical view? What are the implications of seeing it predominantly medically? For the patient it is not only a medical procedure, but the promised land of the rest of their life and this is not often explored in medical transplantation literature. Also if the whole transplantation experience is seen as a medical procedure, only too easily does the patient become identified by the medical procedure. You cease being a person and become a “transplant” – a “transplantee” if you’re lucky.

In this chapter I will describe some significant events that occurred immediately after surgery to show how the medical and the personal narratives were battling for supremacy. After that, I will describe my reactions to three events that all took place years after transplant. They show that my self-perception as a person who has had a transplant is far from straightforward. Although healthy and although my transplant is successful, I still see myself in some ways as “ill”. Why I see myself this way will be explored through writing about it.

Finally, as I have discussed before, I shall examine the idea of being ill all one’s life and then becoming well. This is different from the majority of illness narratives and its implications need to be carefully documented. There is no clearly defined category for people who experience this. Similarly, there is no category for people who have survived organ failure and transplantation; they are not in the same situation as people living with chronic illnesses. For instance, people who are HIV positive, but on antiretrovirals, occupy an unnamed territory somewhere between the well and the ill that is not dissimilar to the “land” where people who have had transplants live. But it is not exactly the same. The disease that destroyed my kidneys is long gone. I am not “HUS positive”. Some conditions that damage kidneys (such as lupus and diabetes) persist after transplant, but many conditions don’t. A new category is needed that will be a more accurate description of organ transplant survivors. It is likely that a new narrative will emerge from this discussion, one that is less the story of an illness, but the story of an individual.

## 6.2 Life post-transplant, the medical view and in-betweenness: The search for a story

Perhaps with chronic illness one has the time to understand and accept that one's life's course is not going to be a simple one of "I was well, then I got sick, then I got well again". My own experience has shown that, although my transplant has been so successful and my life is so normal in so many ways, it can never be a life untouched by illness or loss. And yet that life touched by illness and loss is my life. Your scars are part of what makes you who you are. Taking them away is like erasing your identity.

When you are looking forward to having medical treatment, there is a temptation to believe in restitution stories. You probably would not undergo treatment if you did not hold out some hope of its working. In my case, I really did not know what to expect of a healthy life, because I had never had one. I did once believe with all my heart that any treatment I could have would be better than being in organ failure and that my new kidney would work. In my case it was and it has. Other people's stories have not necessarily turned out so well (as was seen in the section about renal narratives in Chapter 2) and I am fully aware that my future is still not guaranteed, even twenty years later. I can still lose my kidney or develop dangerous diseases as side-effects of my anti-rejection medication.

Nonetheless, I do not see my story as a restitution story in Frank's (1995) terms exactly, because from my remembered experience I am not back to where I was before the "horrid thing" happened. I do not remember such a time, although it existed for eight months before I contracted HUS. Retrospectively, I certainly do not see my story as a restitution story. I have lived in liminal and littoral spaces too long for that.

What might have helped me avoid this way of seeing my story is that, institutionally, transplants are seen in an ambiguous way. They save lives, but they do not cure kidney failure. Not long after I went onto dialysis, my mother and I encountered a renal transplant surgeon near the dialysis unit. My mother longed for reassurance that I would survive and the doctor told her my prospects were excellent, because I was young and otherwise healthy. He explained that transplants could last as long as ten years. I was twenty one. For him that was success: a successful transplant could buy me a decade of reasonably problem-free living. What would happen next? We did not discuss it. He had to run to see another patient. I tried to look grateful, but I felt appalled.

I subsequently discovered that many transplants did not seem to last as long as 10 years. Often my fellow dialysis patients were back on dialysis after failed transplants, not infrequently more than one. After transplant, the general ambience did not become much sunnier. Their

sojourn with their new kidneys seemed fraught with health problems, the medication being one of the major culprits. Worse off than them were the patients who never got kidneys at all, because their general state of health was too fragile. I reasoned ten years were better than none.

### *6.2.1 Medical narratives and being number 548820*

I always felt, after attending my clinics in the awful adult renal unit, as if I had no right to feel tired, sick or afraid, because of the suffering I had seen and also because I was a number. A number with a diagnosis. Such things do not feel pain, emotional or otherwise. The doctors had not diagnosed it or prescribed treatment for it, so it must not exist. On the contrary: they had instructed me to lead a normal life. Each time I went to clinic I felt myself taking on more of my identity as patient 548820, one number in relation to other numbers. It seemed to saturate my bones. Infuse into my spirit. I had a brief respite from numbers in the dialysis clinic for eleven months, but the damage was already done. I'm no mathematician, but it seems to me as if numbers can only exist in relation to other numbers. You can't have a 548820 without a 548819. I have never wondered, until now, who that might have been and what their life might have been like beyond being a number.

Medical narratives compartmentalise you and redefine your identity in terms of your condition (Cook, 1996). In a medical narrative you are a case and not a person. Before transplant I was a "kidney failure due to HUS". Afterwards I was a "renal transplant". My problems beyond my renal situation did not exist. I was defined as being part of a larger narrative of kidney disease, while my experience was that kidney disease was part of me. The human experience of illness and disability (Charon & Montello, 2002) was ignored. As important and as specialised as medical treatment is, doctors ignore human experience of it at a cost (Kleinman, 1988).

My donor had an identity too: cadaver donor 938, but I did not know that when I went into theatre. All I knew was that the numbers had a system and it was not what I had thought. It was not the anonymous, relative system of "Nothing Matters". It was the infinitely worse system of "Something matters, but we're not telling you what it is" or even, "Something is in control of all of this and it is not who you think".

### *6.2.2 A doctor steps out of the medical narrative*

The head of the transplant unit was not technically my specialist. He did, however, have the last word on any procedures I underwent and so he came regularly to my isolation ward to check on my progress. I had always seen him as a strange and cold man who lacked charm or a decent bedside manner. We had had a few run-ins and personality clashes over the years. However, once I was admitted, he came into his own. Not long after my transplant he came to

ask me how I felt and what I experienced. I tried my best to explain how much better I felt, but could not quite put it into words to my satisfaction. I half expected him to tell me how he had decided it would be, but he did not. Instead, he put his head on one side, like a dog listening hard to a sound not audible to human ears.

“I wish,” he said, “that I could experience it for myself. It’s the one thing my science cannot tell me – what it’s actually like afterwards.”

“It’s wonderful,” I told him.

“You do understand,” he said after a moment’s hesitation, “that your transplant is not going to fix everything else in your life?”

Of course I did. The transplant fixed my kidney problems and gave me a chance to fix everything else in my life. What else are second chances for? I did not tell him that I had every intention of making my new life perfect and that I believed I could by virtue of my suffering. I felt I had paid it forward and that my narrative could indeed be a type of restitution narrative.

And yet his remark niggled at me. Nearly two decades later I still recall our conversation because what he said jarred so much with the plot I was covertly sketching out in my mind. I knew literally that a transplant would not fix anything other than kidney problems (and maybe not even that), but, possibly because of my miraculous launch into my new life, I expected strange and wonderful things to follow as a matter of course. I secretly believed it could really be perfect.

I had already made myself a few promises about my new life. I was not one for making promises – I put too great a store on honouring them. They were simply these:

1. I would only ever eat what I wanted, when I wanted it
2. I would never diet again ever
3. I would do everything in my power to keep my kidney
4. I would only do what I wanted to do and spend my precious time on things that were meaningful to me

I have honoured all of them, except the last. I have fallen miserably short with that. I squander (in my mind) vast tracts of time on often repetitive things that gratify other people or that fulfil bureaucratic requirements, but that I find utterly stultifying. Friends tell me this is what normal is. Maybe normal people believe themselves to be rich enough in time to waste it this way, but I don’t and it causes me terrible anxiety.



Every day counted so much more when I was ill. Every sensation was so much sharper. The purpleness of flowers broke my heart. I could not pick them and be responsible for their death. Death flavoured everything, not with decay, but with an acrid poignancy. Since then the urgency of mortality has left me somewhat, other than the inevitable feeling of vulnerability about my own health. That is one locus of familiarity with my previous dispensation.

### *6.2.3 Kidney success, story failure*

Despite the overwhelming evidence that it does not exist, we do still long for a just world. We need to believe that there is a reason, a pattern, that it makes sense. We try to work out what the numbers mean, but we are not mathematicians or even numerologists. None of the numbers in my life seem especially significant, not even in relation to each other. And so we tell stories instead. We hope that someone will listen. People do not always listen if they do not hear what they want to hear: a narrative that fits into their world view. Sometimes we do not listen to ourselves, because we cannot bear to see what the narrative shows.

After many years of a medical story that in some ways was not quite my own and yet was entirely mine, entirely the story of my body and its treatments, I found myself transplanted and alone in a strange new world, with no story, no way of explaining my new circumstances to myself. The tattered remains of my old story did not help me: I had a kidney condition that was deteriorating and I would need a transplant. It was the doctors' story and, now that I had had my transplant, they seemed to feel that they had done their job. Everyone was smiling. The procedure had been a success. All the contact I had with them now was fleeting clinic visits in which they adjusted my anti-rejection medicine. We barely spoke other than to repeat ritually the narrative that I was healed.

Of course that was not quite true and I knew it. I could not be healed. Kidney failure is irreversible. A transplant is merely a therapy and must be sustained artificially by medication. But everybody likes a happy ending. And what is better than a tragic plot that has miraculously become a comic one? It took me ten years to come to terms with the sword of Damocles that still hangs over my head: that transplanted organs mysteriously fail, reject or die, often without warning. Every moment after my surgery has felt like borrowed time, although I have now had my kidney for almost half my life. I have never, in all these years, discussed this with my doctors. They would merely recite numbers to me: odds, probabilities, chances, statistics. They could not help me. I knew no one who could. All the transplantees were in the same position. We would discuss it while waiting in clinic. None of us knew what to do. And the sword fell for many of us. You could not help but notice, even though the doctors never mentioned it. I had come to doubt their narratives over the years and now I felt they had failed

me completely. But I had nothing with which to replace them, other than some strange, small tales of marvellous coincidence.

There are various ways to heal a broken narrative. All of them involve bringing new and powerful meaning to it (Bauby, 1997; Brody, 2003; Bury, 1982; Frank, 1995). Often this takes the form of encounters with the mysterious. This has been seen as a desire for both “healing and the miraculous” being “represented and made real” (Good & Good, 1994, p. 841). I kept reminding myself that despite not having a mobile phone or pocket pager, I had been miraculously “found” on campus on time by the nurse and social worker when my kidney “came up”. This showed me that I was meant to have it and surely this meant I was meant to keep it too. I did not share this with the doctors. For one thing, it deflected attention from their medical procedures and onto the nursing sister and social worker’s resourcefulness and initiative. The doctors seemed not to be so smiley when that happened. Their expressions seemed to become pursed-lipped if I alluded to divine intervention. They would drop their eyes to my file and start reading it until I stopped speaking about my extraordinary good fortune. I needed them to be on my side, so I learned to choose what I told them (Frank, 1995; Weingarten, 2001). But my being found was miraculous. If this happened in a story, it would be seen as a very unlikely coincidence. But it happened in real life, so it must be true.

#### *6.2.4 Turbulent times and an undecided narrative*

Nonetheless I nearly lost my kidney three times in the first three weeks and, after being discharged, I was at bed-rest for two months because of a virus I had after all contracted from my kidney that affected my heart. My body was a turbulence of medications. My blood chemistry was haywire as I battled the side effects of my new immunosuppressant drugs – my appetite increased to gargantuan proportions, I lost hair from my scalp, while it sprouted from my face, chest and back, I broke out in a rash of pimples that I had never had in adolescence, my moods rollercoastered – and, most weirdly, I started to grow in height again, although I was in my twenties. I no longer fitted my clothes. My trouser legs were too short. I had to give away the contents of my wardrobe and get new clothes for the first time in years.

Between the ages of 13 and 18 I had looked much the same, scarcely changing in height or weight. I got thinner in my late teens as I became sicker. Now for the first time I no longer looked like myself or felt like myself. I no longer knew what to expect of myself. I was no longer static. I was changing so rapidly I could not keep up. Was this what normal was? I doubted it. My body became monstrous to me, huge, hot and hungry, unwieldy and perverse. I felt like a werewolf crossed with the Pillsbury Doughboy and I had an overwhelming love of red meat.

Of course I resisted it all strenuously (except the red meat which I ate voraciously). It was as if I had lived in a cave all my life and then had been transported to a rain forest. Light was brighter, sounds were sharper. I could hear properly for the first time in years. My senses were overloaded. And I was off beta-blockers for the first time since I was 9, so the world around me was no longer flattened and two-dimensional.

My narrative was not broken so much as shattered. My identity was in ruins. I was battling a monster and it was me. My body had never been “normal”, but now it seemed truly aberrant to me. It rebelled against me. It became an “inappropriate/d other” (Haraway, 1992). At any rate it was to me. I dysappeared to myself (Leder, 1990). I was filled with shame and cortico-steroid-induced rage. I could not see myself and hence I could not, would not, see my story. There must be something wrong, I decided. Transplant stories all seemed to lead to normality or back to kidney failure. None went where I was going.

Despite this, my doctors were delighted with my (as they seemed to see it) normalisation. In my clinic transplantees were told constantly that they could lead “a normal life” (although we weren’t told what that meant or how to achieve it) and shown examples of other transplantees doing (apparently) normal things, such as holding down jobs, getting married and having children. I had never planned on the latter two, but I now felt pressured to cooperate. Without any discussion of what I wanted to do with my new lease on life, I was lectured on the joys of natural childbirth during one consultation (admittedly the doctor was preoccupied with her own pregnancy). The same doctor in the next breath began expounding on why I needed to have contraceptive injections whose effects would last half a decade at a time, “because accidents happen”. The ward sister warned me that I should not experiment with having children, despite what some of the doctors might say, because it never ended well. All of this added to my confusion.

While the medical team chattered on and on, I remained mute and stymied, unable to speak the language of “normal”, not wanting to learn it. My refusal left me powerless and unstoried. My narrative, always rather tenuous and clinging to a medical narrative of illness, like ivy to an oak, tried to attach itself to the new medical narrative of health, but could not take to such ambiguous and contradictory support and shrivelled miserably. I needed narrative certainty in those days.

It took five years for my physiology to stabilise, although objectively I must say that I improved from year to year. Each year I was surprised to feel more well than I could ever remember feeling and much stronger than I ever had been. I never knew from one point to the next how my life would be. My life had stagnated for so long that I could barely keep up with myself. I

was left breathless and panicky, dazzled by my good fortune and distracted by the smorgasbords of previously forbidden foods. My life was a maelstrom of sensations (and also until-recently-forbidden chocolate, cheese, chips, meat, milk and seafood). No one had told me about the sheer visceral impact of becoming healthy. I should have been warned about the gut-punch of well-being. It shocked my system more than anything ever had on my long, slow, steady decline into ESRD. In that instant that I greeted the social worker and nurse when they found me in a university library, my life changed irrevocably.

#### *6.2.5 I decide on a course of narrative action because of a narrative cut short*

Various writers about illness narratives have alluded to the way we learn about illness through the stories of others (Couser, 1997, 2004, 2009; Frank, 1995; Good & Good, 1994; Weingarten, 2001). Before my transplant I craved stories of life after transplant. My mother and I would go to great lengths to find (non-medical) people who could tell us first-hand how they had experienced it. One man we spoke to invited us to his home for tea and regaled us with stories of how he completed his Master's degree in Architecture, brought up his children, even had a third child and played hockey, (although he wasn't supposed to because it was a contact sport). He seemed so free. He had had his kidney for seven years. Even now "Master's degree" means "surviving kidney failure" to me. I have a Master's degree too. I felt, once I had obtained it a couple of years post-transplant, that I had made it.

However, what I didn't notice until now about my choice of narrative was that all of the stories I chose to listen to then involved life *after* the event, not the event itself. I always wanted to know about the life hereafter. People should remember when they want to know about the afterlife that they actually have to get there first and getting there isn't ever pretty. At this stage I tried to bypass the medical narrative of transplantation by ignoring it completely. The medical narrative was not my narrative, I thought. I am, after all, not a medic. The medics would perform the operation – that was their responsibility – but I would live with the results. I hoped they'd do their job properly, nothing more. In my reasoning, if they did what they were supposed to do, I could live without them and their narratives for the rest of my life, however long that would be. My narrative would be my own at last.

Of course, it didn't work that way. Your narrative is never entirely your own and other narratives that are imposed on you are never truly entirely other. If you have lived so long and so intimately with a chronic medical condition, your narrative is perforce partly medical. If you undergo a medical procedure, you are changed by it. It is written on your body forever. It is in your blood and even in your RNA, if what the inserts on my immunosuppressant medication says is correct about the level of change it causes. It is in your psyche. Part of who you are is what happens to you.

But part of the difficulty of medical narratives is that they are so piecemeal and incomplete, only ever showing tiny parts of oneself. This is of course gratifyingly postmodern, a fractured and partial lens that shows only fragments of a picture (Charon & Montello, 2002; Cook, 1996; Garro & Mattingly, 2000). The problem is that these bitty and partial narratives are seen as reality and whole, leaving no space for any other story. I found that I had to accept the medical version of me and my life to an extent. I wanted, after all, to live. I wanted to be healthy, because I had strength and vitality for the first time in years and I could finally eat what I liked. I did not want more surgery or more invasive medical treatments. I wanted to be left alone. And so I was a very compliant (as doctors like to call it) patient.

To be compliant in those days (and, I believe, now too) meant you obeyed blindly the advice you were given. The doctors are the authorities and you are not. Not only that, but you are viewed as too stupid to learn or understand, so you must not question what they say or ask for clarity. You must certainly not posit any suggestions of your own or attempt to interpret your own symptoms. Sometimes the doctors are very young and inexperienced. Often even the older, more experienced ones have seldom worked with your disease for as long as you have lived with it. Seldom does anyone have the time to listen to what you have to say. Often their advice would make 180 degree turns without warning (Kleinman, 1988) and what you had been told to do last time would now be “wrong” and you would not be told why.

People outside your condition might be sympathetic or curious, but they do not understand how it is living with this new situation. I told an English professor how I found life after transplant and he was quite dismayed and confused. He had thought transplantation was a cure, not a therapy and did not want to hear that I must live daily with the threat of rejection. I learned to pick my narratives carefully (Weingarten, 2001) and not to tell that story to non-renal people.

Patients understand and we spent the long, cold, dreary hours waiting in clinic for our 15 minutes with the specialists comparing notes and drawing our own conclusions about our lives. Generally we were a fearful lot, living under a shadow of rejection and facing a life of medical treatment. We couldn't help noticing how many of us had more than one transplant and how many of us did not survive. The doctors never alluded to the disappearances, I suppose in the hope of preventing panic. Perhaps they believed we were too stupid to notice and would not see unless they enlightened us, because they seemed to think that they chose the narratives and we lived them according to their diagnosis and predictions. We did not talk to them about the deaths. Perhaps that was easier for us too.

As patients we needed considerably more emotional and psychological support than we received. What little we received came from some of the dialysis nurses, with whom we remained in touch because we relied on them for information and advice. It was from one of these nurses that I learned that Eddie Davidson (my fellow paediatric patient who had daringly written about urine and whose poem I used in Chapter 4) had died. He was 25. He had died of a heart attack induced by his antirejection medication. The nurse explained everything to me, trying to console me and I tried to be consoled, but I could not be. She thought I was distressed because I was afraid for myself. This was partly true, but I was actually more distressed because I had lost someone I had known (albeit strangely and from a distance) all my life. I had cheered on his transplants and mourned his rejections since I was 8 years old and he was nine and a half.

Although Eddie and I had never met, we had shared doctors for almost our entire lives and had the same disease. I felt as bereaved as if I had lost a sibling and as terrified as if I were next on the list. Perhaps he was 548819. I never knew his number. I could see his picture in my mind, from photos on my paediatric doctor's walls. I could see his brave poems on yellow cards. I had never seen a picture of him next to other people, but the nurse showed me one of him next to his mountain-climbing friends. He was barely shoulder-high next to other adults. I am a normal height, although smaller than I would have been. Eddie was more stunted by his illness.

At least he did not disappear completely, although his narrative was cut short. His picture remained on the wall in the dialysis unit and everyone spoke warmly of him. As horrified as I was by his short and pain-filled life, its gruesome similarity to my own and his alarming, warning-free death, I was envious of him for one thing: those bits of yellow card. Years after I had seen them their words still echoed in my mind. He had done something I had desperately wanted to do but had never been able to achieve: he had told his version of events. I vowed to myself never to forget his rhymes or his story. I tried to tell the nurse about the yellow cards, but became too tearful to speak. She did not understand what I was trying to tell her and nor did I, until now.

#### *6.2.6 What happened next: Another identity, another number*

I got another number shortly after discharge – a Medic Alert identity number on a stainless-steel oval disc that announced in tiny engraved capitals my condition (“renal transplant on steroids”) and my allergies (Adalat, Maxolon, Stemetil, Vancocin). You had to tilt it against the light to read it. On the other side was Medic Alert's name and insignia (a savage serpent twined symmetrically around a staff, imprinted and painted red). It was like getting a grown-up identity document. Of course, for general (or General) purposes I was still 548820.

I had an identity – I was a renal transplant, for medical purposes anyway. But who was I to myself? I still went every three months to clinic, had many blood tests, charted my urine and took medication every day. I lived in a turbulent body of side-effects. And I had found no way of creating a narrative of my own in the face of an all-pervasive medical story. I fell between stories, my old medical narrative and my new one. I seemed not to fit either, but I had not found anything that would replace them. Moreover, since they were so pervasive, I wondered whether they should be replaced. I depended on medical treatment for survival. I could not pretend otherwise. The medical narrative was still valid to an extent.

### **6.3 Three stories of life post-transplant**

A gap of several years follows after I was “awarded” my Medic Alert bracelet. To give an impression of some experiences from many years later, here are three personal stories: one is of a scholarship interview, one is of a public lecture, and the last is of a patients’ group in Mowbray, where the personal finally becomes public. All of the experiences I have used involved other people and my relationship to them. Together they form a short social anthology or anthropological essay of life post-transplant.

Advances in medical science lead to increasing numbers and types of subjunctive situations. I exceeded the expected amount of time with my new kidney. The doctors didn’t expect my kidney to last after the rejection episodes, but it did. With the advances in medical science and a little bit of luck you might keep your new organ quite a considerable time. It might take a little longer for shared cultural models to develop that adequately explain this new state of extended living through transplantation. Possibly part of the liminality one feels many years post-transplant is a verbal deficiency for a condition or state that is far beyond “transplantation”.

“Post-transplant” is a term like “postmodern”, not especially helpful in that it only tells you it comes after something else and it really needs a term (and identity) of its own. Because the state of being itself is so paradoxical, I am undecided about whether it is a term whose meaning eludes being pinned down by naming or a term that needs stabilisation.

It is strange to find you have a potentially long future when you always saw it as shorter. The subjunctivity continues. This is not the land of possible, even probable death, but rather the land of possible, even probable life. Nonetheless meaning is still contingent. It goes beyond “what it means to be healed when one will always be disabled” (Mattingly, 1994, p. 814). I zigzag between being a patient and a non-patient, and am by no stretch of the imagination ill. My transplant gave me health and strength on a scale I had never previously enjoyed. Five



years after transplant I realised, in my late twenties, that I had not felt so good since the age of 12 or even younger. I seemed to improve from year to year, while my always-well peers were experiencing a slow decline from a glorious youth, complaining of aches and pains, weakness and vulnerability. They longed to be 18 again. I did not and do not even now at 42. So now that I have been transplanted so long ago, who am I? What am I called? What is my condition? Who am I when I am at home and is it different from who I am when I appear (or otherwise) in public?

When people ask me for official purposes (insurance, travel, study) if I have any medical complaints or illnesses, I don't know what to tell them. I have to tell them I have had an organ transplant, but that is not an illness. If it happened in the distant past, is it really a condition? That presupposes that there is an on-going medical complaint and there is none. No, I need new vocabulary. I suspect I may have to make one.

### 6.3.1 Story 1: (Dys)Appearance and reality

*"You look very well for a transplant," said the doctor.*

*She peered at me as if I were a specimen of some sort. She even leaned closer to examine me better. We were at a cocktail party. I wondered what the right response was to a remark like that. The ones that crossed my mind were clearly wrong.*

*You see it wasn't just any cocktail party. It was part of a scholarship interview process that included meeting the interview panel "for drinks". I don't drink alcohol. I never have. So as a non-drinker I find that expression exclusionist. I'm like that with words. I take what they mean very seriously. That whole cocktail party was designed around a certain way of life that wasn't mine.*

*To fit into it, you had to dress a certain way and perform certain conversational rituals. You had to have aspirations of thriving and expanding. Survival is for other people. Healthy people don't understand what it means to struggle to survive or how much effort it takes. They take it for granted as if it is the beginning, not the end.*

*For them everything is neatly packaged in an orderly world. Of course my world overlaps with theirs, just as my medical condition includes health. When we all met for drinks it was 1997 and I had had my kidney (and my Medic Alert bracelet) for six years.*

*The doctor was a member of the scholarship panel. Clearly she felt she had some special insights into my condition, although I wasn't her patient and she wasn't a nephrologist. The following day she and the others were going to interview me. So I realized I shouldn't say*

*what I wanted to say. Instead, I said, "Thank you." She had passed her verdict, I thought. It is customary to thank judges. It is a modern form of obeisance. Would this mean I'd get the scholarship? I hoped so. It was a prestigious scholarship to Oxford.*

*I had wanted to study at Oxford since I was a teenager. Many of my favourite writers had studied there. I loved the history of the place and the architecture. I had dreamed and drooled over the possibility of one day actually being there. I had practised filling out the application forms for the scholarship for several years. I had never been well enough to apply until now at 28. I had written away in previous years to as many of the Oxford colleges as I could and had requested their prospectuses. I had a whole drawer full of them, glossy, full-colour booklets with beautiful pictures. When I had moved with my mother to the other end of the country, I had had to throw away many things, but I had kept the prospectuses.*

*Through all those long years of kidney failure I had somehow always kept going. I had things to live for. My "things to live for" took me through fear, pain, depression and powerlessness. Oxford was one of the things I lived for. Reading, writing, studying and dreaming were things I could do when ill and I was ill for so very long. Oxford was going to be my crowning achievement – proof that I had not wasted my time and that I had something to show for my long years of solitude and deprivation. I twisted my Medic Alert bracelet on my left arm while I waited. Fidgeting helped alleviate the anxiety.*

*I did not get the scholarship. While the scholarship panel was explaining their choice to the rest of us, I looked down at my arm and noticed that I had twisted my Medic Alert bracelet so much that it had broken and fallen off my arm. And for the first time in my life I was truly crushed. I went home. At first I cried, but soon I could feel nothing and so I stopped. Numbly I took all those bright, shiny prospectuses, threw them into a black bag and put them out with the rubbish. All my Herculean efforts to keep going to class and to hand in my assignments, no matter how ill I was, were all for nothing. Nobody understood how hard it had been or what I'd had to go through to get as far as that scholarship interview. I never fixed the bracelet or wore it again. And in so doing I took the first step away from a medical narrative and towards my own.*

*When I had been ill I had often been struck by the barrier between me and the rest of the world. Everything I did that other people took for granted, like eating meals, taking baths, just getting through the day, had required planning and commitment on a scale they couldn't even begin to conceptualise. I had fought relentlessly for my place at university and I had kept it, despite everything. I had never failed anything, never had to rewrite*

*anything, never asked for a single extension. It was a matter of honour. None of that counted. No one knew or cared. Once again I felt like a veteran returned from a distant war to live among people whose lives were completely unaffected by it.*

*My mother realised how not getting the scholarship had affected me. She even offered to sell the house she had struggled to keep for so long, to pay for my fees. A year's study at Oxford would cost R100, 000. Our house was worth only three years' study, probably not enough for a degree. The exchange rate was not in our favour. (When I first wrote "favour" I "accidentally" wrote it as "failure".)*

*I decided to continue with my doctorate at a local university, but I couldn't. I was completely unable to continue with anything academic, although I made a number of false starts. You might say I entered into another liminal period, this time of academic existentialism, where nothing had any value and nothing mattered. It took me 10 years to get over that and to become a phenomenologist again.*

*So for 10 years I did nothing academically. It was easier to do that than to reflect on how different my life might have been had I not been so ill for so long. I cannot, even now, bear to think about how different my life could have been and how much richer. I dare not wonder at what my achievements might have been, because then I have to admit I am probably leading a shadow life. I so badly wanted CKD not to matter to me. After all it seemed no to matter to anyone else.*

*Before dialysis and transplant, at university, when I was so frail I couldn't climb stairs anymore and was sleeping for 14 hours out of 24, the Disabled Students' Programme told me I wasn't disabled enough to deserve any help from them. While I was waiting for a slot on dialysis, my father (a medical doctor), who was dragging my mother through maintenance court with monotonous regularity (eight times in 15 years) told me that I should get a job and support myself, since I was over 18. The postgraduate supervisor told me she couldn't be bothered to re-set an exam for only one student and if I didn't think I could manage I shouldn't register. My doctor told me to get on with my life and not let ESRD hold me back. His message seemed to be that it shouldn't hold me back and if it did, it was due to some inherent weakness of my own character. Their stories of my life were so powerful then.*

*I did not want to be weak. I wanted to do what others did. I also really wanted to use my second chance at life. So when I had my transplant, I decided to push on with my plans. At last I could. In all honesty, during all those years of debilitating ill health, I hadn't thought*

*much beyond getting a doctorate, possibly because deep in my heart I knew that I was dying.*

*When I failed to get the scholarship I felt as if my entire world's foundations had been destroyed. Everything I believed in collapsed and my second chance suddenly seemed very long and very empty. I saw no point in it at all. I had been judged and found wanting. I had not been told how or where I had failed, just that I didn't make the grade. ESRD and its treatments were such a large part of my life that I could only understand my failure in those terms: I was too defective to study further.*

*Only now a decade later am I able to commit to a doctoral topic. Only now can I bear to study anything again. I am registered at a local university and I have been awarded a local scholarship. I would not consider applying to study abroad again. In fact I have refused to do so, although I have been assured I have as good a chance as any of getting funding. I know better than to believe that. I am convinced that I got the local scholarship I did because in the documentation I had to fill out I never told the trustees that I have had a transplant and I kept any description of my topic vague and general. Although well ("well"), I did as Antonio Batista did on dialysis (Hutchinson & McCallum, 2000): I kept my condition a secret so that I would not be penalised.*

*It's better not to tell. I had told the first scholarship panel that I had had a transplant for two reasons: a) I thought it transparent to do so, and b) I thought it showed what I had achieved against the odds. I did not take into account that having a transplant may have meant something different to me than it did to people who had not had one.*

### 6.3.2 Story 2: The past is foreign country

The past may well be present, but it is in a sense irretrievable. It is gone and known only by its effects. You cannot go back there. Unless you have a visa. With chronic illness or conditions that require life-long tertiary care you always have a visa to return. The visa is expensive, but life-long. You are expected to use it regularly to attend clinic, have blood tests, buy monthly medication.

No, let's be honest. It isn't a visa, as much as we might like it to be. It really is a second passport – or in my case, a first passport. I immigrated after transplant to (I thought) the land of the well, but it is not my country of origin. People usually hold dual citizenship, but don't know it until something goes wrong (Sontag, 1978). For those of us who have never enjoyed robust good health, however, we experience this to an extent in reverse. It can be quite a surprise to

discover that the citizens of the other land view you as one of them, when you expected to look foreign.

But if you belong to both countries, the land of the ill and the land of the well, then you don't truly belong to either. You certainly don't belong fully in your new country. In some ways you still live in your old country. I am reminded of that in little ways even now all these years later. It is not (usually) my new fellow citizens who remind me of this. When we have functions at work and the food is laid out in a buffet, I can't get enough of it even now. Chicken wings are my weakness and cheese, cold meats and olives. I eat as much as I possibly can and hope no one notices. These were forbidden foods when I was growing up. The cakes, scones and puddings often have cream, especially the scones. I take the cream and leave the rest. I've learned not to do this when people are watching. I sneak into the kitchen afterwards and help myself to spoons of whipped cream from the bowl. Sometimes it's Orley Whip. I cannot describe my disappointment when I taste its familiar oily nastiness. Then I have to flick what's left on my spoon into the dustbin and rinse out my mouth. I cannot believe that people can eat that awful stuff willingly.

I have started taking "holidays back home" again after all these years. When I left Johannesburg in 1995 I left behind the transplant world and my connections to it. I never formed new links with the transplant and dialysis community in the Cape. Until now. When I started my research I contacted various medical kidney groups to see if anyone else was doing similar work to mine. This led to my giving a paper at the South African Congress of Nephrology. This in turn led to my being invited to give a talk at a patients' group in Mowbray. It meets bimonthly. I've been attending it on and off ever since.

I was also invited to attend a talk by a visiting American renal transplantee and motivational speaker, Lori Hartwell. She has a site (<http://www.lorihartwell.com/>) and a book, which she uses as resources to inform healthcare professionals and patients about renal issues and the experience of renal disease. I extended the invitation to a friend I had made at the nephrology congress, Minette. She had her transplant in 2008 and we had both given a paper at the congress. She travelled all the way from the Eastern Cape to hear the talk.

I met Minette at the Waterfront and we drove together to the lecture. The talk took place in one of the lecture theatres at Groote Schuur. It was attended primarily by patients, but a number of nurses attended too. I didn't see many doctors there. I wrote about Lori Hartwell's talk and my reaction to it afterwards in my journal:

*I was struck as I listened to her by how similar in many ways her story is to mine: she was born about two years before me and fell ill in the year I was born. Her kidney failure was*

*caused by something that can be a factor in what caused mine (HUS) – e-coli. I bounced back more because I was younger. Babies are more resilient than children, even toddlers. We fell ill in the same year.*

*We grew up ill. She did ice-skating. I did gym. She had three transplants. I had one. Her last one was the year before mine. She takes me up to my shoulder.*

*Watching her and hearing her tell her story I thought, “But for the grace of God go I”. Then I realised that basically her story was my story. And I realised I had protected myself from that fact.*

(Richards, Research journal, 2008)

What I realised in attending Lori Hartwell’s talk was that until then I hadn’t really seen my own story. Seeing a similar story through someone else’s eyes made me realise paradoxically how fortunate and how unfortunate I had been. Lori Hartwell had three transplants, compared with my one. Two of hers failed and she had to live twice through the misery and trauma that follows. I nearly lost my kidney after transplant. I had two acute rejection episodes and one chronic one, which almost cost me my kidney. Waiting for your transplanted organ to die is the worst feeling in the world. But my transplant survived. Because of this I was only on dialysis for 11 months, instead of years.

She’s taking the same immunosuppressant medication as me because our transplants are of the same vintage. Transplants these days are treated with new medication. My nephrologist explained that the meds I (we) take are like firing cannon balls at your immune system. They take out many parts of your body’s natural defences. These days the new medications are more like snipers. They target specific parts of your system and leave the rest alone. My nephrologist pointed out that I am on half the prescribed dose of my meds, and that they work well and are cheap, so he is loath to change them. I trust him. He’s taking them himself for another condition, so he has intimate knowledge of their side effects. This is the only time in my forty years of medical treatment that I have ever had a doctor who really understands that.

Lori Hartwell’s growth was stunted by her illness. I remembered Eddie. I didn’t realise we were so ill. I finally understood why my paediatric doctor had spent so much time poring over my growth chart and discussing how close to the edges of normality my growth cusp was. It had been pretty borderline, from what I could see across his desk. As a child I thought that meant I was just small or growing slowly. Now I see that was so, but paradoxically I was tall, really tall, for my condition.

Although I am a normal height for an adult woman, I am smaller than most people in my family. In fact a recent family picture makes that laughingly clear. Their heights range between five foot eight and six foot five. I am five foot four. So I'm a normal height for an adult, but not normal for an adult in my family. After my mother's death I had wanted to keep some of her clothes to wear, but they were all too big. I thought nothing of it at the time. Mom was always bigger than me.

When I saw Lori and realised she was so small because of her medical history, I was grateful that I had not turned out the same. I managed to defer dialysis and my transplant until I was in my early twenties. I even grew a couple of inches after transplant. That was strange: after being the same height for years, I suddenly found myself too long for my clothes and looking down on people I was at an eye-level with before.

My story is not identical with Lori's, but it is similar enough for me to have to confront once again how serious my condition was and in some ways still is. Now it seems I have been doing the same thing my doctor did – telling myself for years that all is well, while walking on a knife-edge between sickness and health. Despite seeing Eddie's smallness in that photograph all those years ago, I still didn't see. I could not afford to see then. And yet both stories are true. On the one hand, I am well ("well") and I can lead a normal life. On the other, my circumstances are anything but normal. I could not talk about Lori Hartwell's talk for a day afterwards. I could not discuss it, not even with Minette. I felt drained and shaken as if I had been in an accident.

*I felt myself going numb. For the rest of the day I was tired and dazed. I withdrew into myself. A deep part of my mind was processing something. I did not know what it was. When driving Minette back to the Waterfront I spaced out at a traffic light, but can't say what I was thinking about.*

*I didn't talk about it until the following evening when a young colleague stopped to talk to me and as I told him about the previous day I found myself choking up and tears flowed down my cheeks. It was a strange way of crying, because my heart rate didn't go up nor did my chest hurt. It was as if I could feel around my core, but not in it – as if that core was protected and veiled from me – or that I was protected from it. I felt numb and alienated from myself, as if I had recognised my alienation at last.*

(Richards, Research journal, 2008)



Was this dysappearance? I felt ashamed of my tears, although my colleague assured me that they did not bother him and that my reaction was normal. So I did not dysappear completely, although I could not stop crying, which embarrassed me.

### 6.3.3 Story 3: The return of the native

Another absence. I didn't write anything about this in my journal. And I still don't name it in the heading of this section. Is it so unspeakable to me? The first support group meeting I attended was an end-of-year party.

*When awaiting a place on dialysis I longed for a patient group so I could hear how others managed the monstrous situation in which I found myself. While on dialysis I found myself running (very briefly) a patient group on request of my doctor. The social worker and I devised a questionnaire which the patients filled out and from this we discerned (amongst other things) that a group was needed. We only held one meeting before I was called to transplant. As a transplantee I again longed for support, but by then was feeling well enough to create an informal support structure with other patients as we whiled away entire days waiting in clinic to see doctors. Then I moved away to the Cape and didn't connect with the transplant groups here.*

*By then it had been a few years post-transplant, I felt well and enjoyed not having too many reminders of my condition. My clinic visits became fewer, from every three months to once a year. My medications were reduced. I lived outside the city where my clinic visits were. At Groote Schuur I didn't even have to see a doctor unless something was wrong. Nursing sisters took all my readings, did all my tests and made all my appointments. I didn't see a doctor in over a decade – the only nephrologist-free decade in my life. For the first time ever I didn't have a specialist. I felt wonderfully transgressive.*

*By the time I joined the patient support group I had already acquired a new nephrologist, but I had not seen another renal transplantee for over a year. I had only glimpsed them in clinics since 1995. I arrived early at the first meeting in Mowbray. I wasn't sure I'd find the Town Hall easily, but I did. It was in the Main Road, in between the First National Bank and the library, just as Nadeema had told me. I had met her at the congress. She was a renal nursing sister with 40 years' experience. She started in the year I was born, so she has as much renal experience as I do, although of a different sort.*

*As I pulled into the parking lot I noticed the Town Hall was next door a building that permanently housed a cancer support facility. The library and cancer support building were closed. Everything was damp. It had been raining. The tarmac of the parking lot was*

*crumbling. I could hardly see the parking bays because the paint had worn off. Little pools of water lay in holes, amid weeds and long grass. Red-winged starlings chattered in the coconut palm. The place smelt of wet tar, pollen and exhaust fumes.*

*The Town Hall itself stood apologetically off to one side of the property, as if scuffing its shoes and whistling nonchalantly. It was smaller than the small library and much smaller than the cancer building. In fact it was smaller than the little town hall of the small town where I live. Its gesture towards Cape colonial vernacular looked mouldy. The beige paint was peeling and the wooden doors and window frames were rotting. Outside in the street, beyond the iron railings, walked dubious personages dressed in hoodies. Some walked quickly as if running late for a crime spree. Others loitered and peered at me from beneath their brows. I hoped the car would be safe. I hoped I'd come at the right time and that the long drive would be worth it.*

*A single car was parked in front of the building whose yellow wooden doors were open in a gap-toothed welcome. A small, bedraggled group of people stood on the cement steps. They peered at me too. They looked as if they were waiting for a lift. I drew closer and peered back.*

*I recognised them although I had never met any of them before. They looked like me. We came from many different racial and cultural groups but we all looked the same. Cortisone does that to you. You develop a very distinctive facial shape and a certain type of facial hair growth. The closer I got to the group on the steps the more like an extraordinarily cosmopolitan family portrait they seemed. They recognised me too although they had never seen me before either.*

*Inside, lots of dark red plastic chairs had been set out facing a small stage. The room itself was painted yellow, with white trimmings and the stage had voluptuous rose-pink curtains festooning it from floor to ceiling. The ceiling was very high and moulded, although the paint hung from it in strips. The walls were stained as if the room had been filled with water at some point. There was a little gallery at the back of the room. No one was in it. Instead everyone crowded into the area with the chairs. I wondered why as there was no air-conditioning.*

*My question was soon answered. After a short talk advertising future events and thanking people responsible for various things during the year, Nadeema invited us to enjoy tea and refreshments. These had been laid out on several trestle tables in a side room that led into a small decaying kitchen.*

*It was a feast of epic proportions. A team of Malay caterers had poured their hearts and souls into the mountain ranges of coconut-covered tartlets, twee gesiggies<sup>8</sup>, ystervarkies<sup>9</sup>, spring rolls, samoosas, miniature chicken pies, milk tarts, lemon meringue pie, koeksusters<sup>10</sup>, coconut-dusted doughnuts, curry-filled pastries, fragrant baby vetkoek<sup>11</sup> stuffed with mince, miniature vanilla cakes with different coloured icing (green, pink and yellow) and homemade butter biscuits with shards of glacé cherries on top. Foothills of pretzels jostled with highlands of potato chips. Lakes of boiled sweets twinkled between promontories of whole fruits. Rivers of tea, coffee, juice flowed into landfills of paper cups.*

*The patients fell upon the tables like children at a party. They had been waiting for this for some time. Even really sick-looking dialysis patients with external shunts stitched into their necks perked up and grabbed plates piled high with goodies. Amid the mêlée I saw two dialysis patients I had been sitting next to during the talk. They were wolfing down lemon meringue pie and paper cups of fizzy drinks.*

*“Are you guys allowed to eat this sort of thing these days?” I asked naively.*

*“No,” said Martin thickly through a mouthful of pie. “But ‘s okay.”*

*“We dialysed longer this morning so we could have lots of cold drinks too,” Mary explained, tossing off her second paper cup of cola. “Did you get some of the chicken pies, Martin?”*

*A whole room full of people who ate just as I did. For once I didn’t have to worry about looking greedy. I didn’t have to resist that aching need to grab as much of the food as I could and to devour it as if there was no tomorrow. I had a cup of tea and nibbled a heavy, crumbly butter biscuit. Somewhere in the thick of the feast one of the caterers had handed me a yellow plastic plate heaped precariously with goodies from apparently every platter. For once my own uncontrollable appetite had deserted me.*

*It didn’t matter whether we were in ESRD, on dialysis or post-transplant. We’d always be starving. I noticed several people carry away platters for afterwards. I knew what would happen to it too. It would stand on the kitchen counter until it went stale and then after days of deliberating it would be heaved into the dustbin. But they’d wait until the bitter end before parting with it, just in case it miraculously became unstale again. Just in case they deemed it all right to eat forbidden treats. Just in case no one was watching...*

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<sup>8</sup> Twee gesiggies (literally “two little faces”) are little square sponge cakes with icing in two colours.

<sup>9</sup> Ystervarkies (literally “little porcupines”) are lamingtons.

<sup>10</sup> Koeksusters (no meaningful translation for this) are deep-fried, twisted dough saturated with sugar syrup.

<sup>11</sup> Vetkoek (literally “fat cake”) are savoury doughnuts.

*The familiarity of it all shocked me. We looked alike. We behaved alike. I knew exactly why they did as they did. The world made sense again and in realising this I realised that it had not made sense for a long time, although I had inhabited it without truly noticing. I felt as if I had come home. I felt as if I had never been away.*

#### **6.4 Recursiveness: The return of 548820**

What a bleak heading after such a long experience and such lengthy supporting narratives. Have I come all the way through ESRD, dialysis, transplantation and a long healing process only to return to a condition I resented and that dehumanised me? That is not a comic plot. It is also not the purpose of autoethnography, which attempts to redefine situations and to capture the in-betweenness of life that is so elusive. In life and in narrative you cannot really go back to what you used to be. I am, of course, myself now and number 548820 (if it has not been destroyed) only exists in some file morgue in the bowels of the Johannesburg General Hospital, because I am no longer a patient there.

The recursiveness to which I refer is that sense of recognition of my fellow transplantees, understanding lives that are similar to mine in ways that non-renal people never can. It is the belated recognition of my own trauma and distress, and seeing it clearly for the first time from a distance of years was devastating. Autoethnographic writing allowed me to do that because it allowed me to write about my feelings and to be analytical, against a context of renal narratives and other illness writing. It forced me to look more closely at these, instead of looking away. It made me see my disablement and name it. But it also made me see my power. It allowed me to go back, because it provided a contained way of doing that.

As painful as these three stories were to relate and as distressing as the experiences were to experience, writing about them in this way allowed me to see past other stories into my own. And I was amazed at what I saw.

##### *6.4.1 Dysappearance and reappearance*

Writing about the doctor who told me I looked very well for a transplant, I was at first filled with shame. I felt once again the feelings I had experienced when she said those words to me. I was forced to see from a distance of years and through older eyes that her narrative, a medicalised narrative, had the effect on me that it did because I bought into it. My internalised narrative had been so rudimentary and so damaged that I had resorted to seeing myself through a medical narrative instead.

When I wrote my story – the first time I had actually committed it to paper – I was so filled with anxiety and alarm that my palms sweated and my hands shook. My heart was in my mouth.

What would I see? I could not bear to look more closely until I wrote the next two stories. The “liminality” I experienced, the in-betweenness, did however start to niggle at me. I had tried in previous years to overlook it, because it was painful and left me feeling as if I had failed at being normal. Often transplantees want to return to normality if they have experienced it before or to attain it if they haven’t (Crowley-Matoka, 2005).

I look normal, especially now that my cortisone dose is down to 2.5 mg a day. But I have had a transplant. At some level I am not “healthy”. I was reminded of this after the emotional rollercoaster of lowering my cortisone by 2.5 mg for the first time in more than 10 years. I had flashbacks to what I used to feel many years ago when I had first had my transplant: a dread like vertigo, and the realisation that you know you are walking along a cliff and dare not look down. I get the same feeling when reading about people whose transplants have failed, such as that of Kristine Shapiro in Hutchinson and McCallum’s anthology (2000). So much depends on those little white pills. My doctor was cautious too; he had me lower the dose in increments, with frequent blood tests, so we could nip any problem in the bud. And yet I am not really ill. I survived the 2.5 mg drop in my cortisone and continue to flourish.

The “liminal” state in which I find myself is one that has been sustained and persistent (Crowley-Matoka, 2005; Little et al, 1998) now for nearly twenty years. It is an in-between condition, but it is not really liminality as defined by Van Gennep (1960) or Turner (1969). It is not a ritual condition to mark the advent of a new identity. It is not even a waiting period between two states, as it seems to be constructed in literature. It is something else.

It is a different state from when I was on dialysis (Richards, 2009a, 2010). Liminality on dialysis was the result of protracted, severe illness mitigated by life-support and was a waiting room between succumbing to a fatal disease and receiving therapy that might save my life. I am well and yet I depend on tertiary health care to sustain my health. I am sometimes reminded of how fragile that health is. I am between sickness and health in a way I find difficult to pinpoint. I occupy a third space now, but it took me some time to understand this.

#### *6.4.2 Haunted by other people’s words and a medical narrative*

And then of course there was the little matter of the words themselves that the doctor at the cocktail party used. In her eyes, I was a transplant, a medical procedure and nothing more. I was the sum total of what her science could do. I think I had been so distracted by what the words meant that I had not seen their deeper meaning.

It took me a while to understand what the doctor meant when she said, “You look very well for a transplant”. She meant I was not supposed to look well. I was supposed to look ill, because

in her eyes I was ill. I had something “wrong” with me. All I could ever be was a pathology. All that medical care, only to continue to be ill.

Years later, when I first saw my private nephrologist, he explained that, contrary to what the ebullient surgeon had told me near the lifts nearly two decades before, when I had had my transplant, only twenty percent of transplanted kidneys were expected to last as long as ten years. At the time of the interview I was already in year six. I imagine the panel took that into account. It doesn't sound like such a bargain if you pay thousands for a student to get a degree overseas only to have her come back and go straight into kidney failure in year ten. Statistically speaking, I was a high risk.

But of course, I am a person, not a statistic. In year six my kidney had settled down well and all my results were normal as if I were a person who had never had any kidney problems. Twelve years later they are unchanged. I am not a procedure either. There is so much more to me than what doctors can do to my body. I have always known this, but their narratives still affect me.

In writing about the experience I came to see that unwittingly and ironically I had begun almost immediately recomposing the story of looking very well for a transplant. The story itself was ironic, about looking well, although not being well, and of not looking how you are meant to look when transplanted. I enacted wellness ironically. With so much irony to cope with, it has taken me years to deconstruct it and reconstruct it. Her story enraged me. But I could not altogether reject it for it was in some senses true. I had had a transplant and I did, indeed, look well. It took many attempts and retellings over many years to wrestle that particular demon into submission. Living past year ten and every subsequent year with a healthy kidney has made me stronger.

#### *6.4.3 Lori Hartwell and narrative breakdown*

My ironic narrative came to an abrupt end when I attended Lori Hartwell's talk and was forced to see that some of us don't look well at all. Lori's life was in many ways so similar to mine that recognising her otherness made me confront my own, although mine was less visible. A narrative of looking well and being ironically not what I was meant to be was clearly not adequate for my circumstances. It had to evolve.

It was at this point that I went the other way. I stopped trying to pass (Goffman, 1963/1990) and labelled myself disabled. At first I only write this in my research journal, to give myself courage, but then I started saying it out loud. An article I reviewed for a journal confirmed this. It was about transplantation in Spain where people who have had transplants are categorised

as being between 17% and 24% disabled. At this point I “came out” as a transplantee. Once I had started I could not stop. I dragged my condition into everything. My stock opening phrase for any conversation became, “As an organ transplantee...”

Although I had become a conversational bore, this allowed me to try out a new identity in public. Most of my friends and colleagues went along with it, although I could tell it wore on their patience after a while. Labelling myself as “disabled” bothered them a lot more. The reactions range from fascination to puzzlement to viewing it as inappropriate. This amuses me. At first I thought that those few who view it as inappropriate found it too personal. Instead I came to see that they found it too medical, too biological and too “dirty”. Talking about such things breaks a social taboo (Douglas, 1966). It should only be done by people authorised to do it (such as doctors) and only about other people. Serious medical treatment and terminology are reserved for the “disabled” and “abnormal”, those who are not like “us”, those who are spoken about, but who do not do the speaking. Well, I am not like “us”.

One friend tried to convince me that I should not see myself in that way. A colleague, like the Disabled Students’ Programme from long ago, maintained that disablement was for conditions such as blindness, deafness or paralysis. I ignored them. The more often I described myself in these ways and told the story of my condition against this background, the more comfortable I felt with it. But this too was not adequate. My notes at the time show me wrestling with the unsatisfactory nature of liminality and a longing to belong somewhere. My story was evolving without my realising it.

#### *6.4.4 Safe to go back*

At first I attended the patients’ support group because I had been invited to give a talk. I felt reluctant going there. I had stayed away from such things for so long, more than a decade, and I had not missed them. Now I attend sporadically because I want to show my fellow renal patients support. I find it emotionally draining, but in their company, I am with people who are like me and that offers me a curious type of validation.

I would not have been able to do this a decade ago. Perhaps it is the distance of time and a successful transplant that allows me to participate as I do. I always leave remembering how lucky I am. Most of the regular group members are very unwell and experience a lot of complications. I have noticed that those of us who are healthy come less often. And then there is the usual amount of dying. Twenty years later that seems to continue unabated.

So my story remains partly medical and partly personal experience. I do think, however, that it is more my own now. I started attending the patients’ group some months after I attended Lori



Hartwell's talk, so I was primed to identify with the group members and to see myself as disabled. In the group, however, I have had to oscillate between being well to the seriously ill patients (who ask me longing questions about what being well is like) and ill to the medical people and social workers (who ask me how I am doing under the circumstances). All our conversations seem to begin with what caused our conditions and what our creatinine levels are.

This had made me realise that this is what my identity is. I am comparatively well and comparatively ill, sometimes at the same time. I am always, however, double and always in "transplant land". I have come to see that this is not liminality exactly.

## **6.5 Littorality not liminality: A never-ending story**

Acknowledging the extent of my own disablement from ESRD and its repercussions on my life and on my psyche has taken me my whole life until now. Even now as I write about it I can feel my attention wilfully wandering off to think of better things. When I first acknowledged it in my research journal, I cried (research journal entry, 30 June 2008). I tried to write about it, but did not succeed until a few days later (3 July 2008). My disablement means stigma, vulnerability and otherness. It means marginalisation. It means being simultaneously visible and invisible. In other words, it means disappearance.

It is an in-between state from which no amount of ritual can retrieve you. Once you've crossed over there you're like Eurydice, lost forever. If you're lucky you're more like that boundary-crosser, Persephone, who can sometimes return to the sunlit land of the living from the obscure, infernal regions (Lionnet, 1989). But you always have to go back. This is described in some of the literature as liminal (Crowley-Matoka, 2005; Little et al, 1998). Is such a condition truly liminal? Liminality is, by definition, transient and bounded (Turner, 1969; Van Gennep, 1960). It cannot be protracted. It represents anti-structure, but is not itself anti-structure. By its very attempt to reinvent anti-structure, it interprets and orders it, controls it and tames it so that it can safely be passed through from one structured state to another.

Liminality, in short, is part of a ritual that allows people to explain how a person moved from one status to another in society— how a woman moved from being single to being married, or how a boy became a man, or a novice became a priest. Illness and disability are not part of a ritual condition, although they can be contained and represented or even understood by one to some extent.

Writers such as Brody (2003), Crowley-Matoka (2005) and Little et al. (1998) speak of extended or sustained liminality very compellingly. But I wonder if that is truly what they are

describing in chronic illness. The conditions they speak of seem less like liminality and more like limbo. Limbo, however, is usually an in-between state too. It ends when you have done your penance. Maybe all I need is a good ritual of reintegration (Van Gennep, 1960). If I underwent such a ritual successfully then I could return to society in a new guise and occupy a different and elevated role. I would have a new identity too. But here I falter. What would my new identity be? And what if I have had it all these years, but have not had the right name for it? “Transplantee” does not truly capture who I am, because I am more than a person who has undergone a medical procedure.

Perhaps I can best describe myself as littoral. I prefer this because it extends beyond medical procedures into my life as a whole. In life one is usually on the way to something else or oscillating between identities, but this is clearer than ever when you are living with chronic illness. Finding this word, this new, clean term, uncluttered with psychic baggage and unburdened with metaphor has been extremely useful to me in understanding where I am today and who I am. The stories in this chapter are part of my journey to attaining an understanding of my post-transplant identity. Each experience and each version of the stories allowed me to move towards a sense of identification that was complex enough and nuanced enough to meet me where I am now.

I am fully aware that if my condition were to change I would change my perception of my littorality. If I were to return to dialysis and re-enter a liminal place, I would have to redefine the last twenty years, because the littorality would be bounded and would in retrospect seem more liminal than it does now. Similarly, if I were 20 years older than I am now, my perception of the forty years since my transplant might cause me to have a different view of my littorality, which at this point I can't even imagine. If miraculously a cure could be found for kidney failure and my “old” kidneys could regenerate, I might look back on life post-transplant as a waiting room. If I chose to regenerate my “old” kidneys. I feel a certain loyalty to my “new” one and would be reluctant to dispose of it.

But as things stand now, I see that I can be both “well” and “ill” and something else. My body changes as normal people's do. I may always be Other to some, but I am no longer Other to myself. I know who I am. I have reappeared. I have come home. I would not have been able to do this without conducting an autoethnographic study. I must grudgingly admit I would not have been able to do this had I not been propelled into taking this journey through a series of unfortunate events, starting with a mortgage company that refused me health insurance.

## CHAPTER 7: CONCLUSION: INHABITING THE LITTORAL ZONE

### 7.1 Introduction

Writing my story, making and telling it, has led me to this literal and metaphorical place, both in my dissertation and in my life. Malinowski (1922/1984) recommended that, when carrying out an ethnographic study, one should try to see what the indigenous people saw of their own world, but as an outsider. One should not “go native”. But I was (and am) an insider and writing this story has helped me find that again. At least sometimes I am on the inside and sometimes I am on the outside. My situatedness changes when I least expect it.

When I tell the story I am an outsider, while when I live it (and am told about) I am an insider. As an outsider I flee from identity, while as an insider I flee towards it. As an outsider I disappear, while as an insider I reappear. My story does not have a first- and third-person narrator, but in effect I too move towards and away from cultural place and identity (Buzard, 1999). I want to be seen as myself, but I also want to be seen as a product of a certain set of experiences. I am not who I would have been without them. I need to find where my disappearance can be prevented, where I can reappear.

In writing an autoethnography about my experience of chronic kidney disease and its therapies, I moved between two writing cultures, academic (different types of qualitative health research) and biographical (illness narrative). Although ontologically very different, they are related in terms of certain epistemological goals. This can be seen particularly in writing about individual experience of medical conditions, interpreting the meaning in such a way that the experience can be shared with a broader audience (whether academic, medical or people living with the condition) to raise awareness and provide insight or at least a discursive space.

My intention was that my autoethnography would be a *métissage* of these two cultures and would emerge as a type of third space where writing about CKD and life post-transplant could be explored. Writing this way gave me a new understanding of the complexity of my life pre- and post-transplant. It allowed me to reconceptualise the binary of well and ill so that I was able to find a strange and shifting third space that I could inhabit: the littoral zone. It allowed me to reflect on my own writing as well as that of others who had addressed the subject of renal disease and illness narrative. Doing this has increased my conceptual repertoire about kidney disease and has shown me that much more work can be done in this area.

I have found my autoethnographic journey to be both theoretical and pragmatic. Sometimes the bricolage-like quality of working with the resources at hand (my few artefacts, my memories, my narratives, other people's writing and research) left me feeling rather destabilised and longing for epistemological certainty. But this very uncertainty was a most fertile area for developing new ideas about ambiguous or even contradictory situations (Shildrick, 2002). The practical aspect of using writing as method of discovery can prevent theory being privileged over experience, if the writer remains aware and self-reflecting.

For instance, in recognising my otherness – my “disability” – and by making it visible I had to change the story of my self. Paradoxically by making my identity and my story visible I made myself disappear (Leder, 1990). My self became monstrous to me, because it “confounded normative identity” (Shildrick, 2002, p. 5). I felt ashamed of being disabled and this at first caused me to see myself as monstrous, as only my “abnormality”. Then I felt perturbed because my identity did not fit into a normative category, being between well and ill, able-bodied and disabled. Normative categories tend to be absolute. As I negotiated the experience of being disabled and other and seeing myself being disabled and other, the old version of my perceived self disappeared and was gradually – still is – being replaced by a new version that I am coming to understand.

At first I thought this instability of identity occurred because I had had a transplant. My circumstances are, have been and will continue to be so very changeable. But I have come to see that the standard body is unstable too (Shildrick, 2002); it changes, it grows, it heats up, cools down, has scars, has wounds, heals, hungers. In this (postmodern) way my well/ill positioning is standard now, even if my physiology is not (yet).

And so we are back where we started again. While writing my dissertation I have continually been struck by the non-linear nature of my narrative. The past is always present on so many levels. And the present is the lens through which I see my past. Both past and present are palimpsests (Derrida, 1978). It is almost impossible to write this story in chronological order. The previous chapter was meant to be about what happened after the transplant and yet in certain ways it is so much about my identity before. But I can't write the past in the past. I found that when I tried to take snapshots of all those years of CKD and ESRD. I have to write it from an ever-changing present. I notice too that in so doing I am starting to inscribe for the first time a tentative (if immediate) future.

In this chapter I draw together some of the threads of my dissertation and braid them into a conclusion of sorts about my autoethnographic experiences.

## 7.2 Boundedness and thresholds, breakthroughs and openings

Rituals create boundaries. They structure experience and demarcate it so that it can be contained and understood. They give it a beginning and an end. Narratives are ritualistic in this sense. I was keen to write my narrative because I needed a ritual that would structure and contain my renal experiences and (I hoped) provide me with closure, so that I could leave the past behind. Of course it did not work this way.

When I started writing the chapters in my research I had wanted to tell “the whole story”. I saw writing the dissertation as my opportunity to be able to unpack forty years of experience, to analyse it and finally to be able to make sense of it. I leapt right in. I came to see, despite every effort not to, that I was not going to be able to tell the whole story after all. The story itself was not whole. It was certainly not complete, because it was not finished – I am, after all, still alive. I suspect that even when I am not, the story will still be incomplete, ragged-ended, patchworky and parti-coloured.

I could not escape telling some version of the medical story (although I had badly wanted to avoid it, because it had dominated my life for so long and had stifled my own personal story), because without it my own story could not make sense. I felt ambivalent about this revelation. On the one hand, I felt that my story was connected to a greater whole and that, while the greater narrative influenced me, in some small way I might influence it as well. On the other hand, I felt alarmed that the very narrative I was trying to escape followed me like my own shadow.

Most perturbingly, the narrative was not really one story at all. It splintered, fragmented, reinvented itself, even sometimes contradicted itself. I was forced to accept that this was how it was and, after this, it seemed artificial to make it one neat package. But time was short and so was life. I did not have forever to write the story and was certain that readers would not have forever in which to read it. And so, because of all of this, I demarcated the edges of the story.

In the telling and the retelling of it, its postmodern nature re-emerged. I found some ways of crossing boundaries, some changeable spaces that remained in my new-found fearful symmetry. Something that paradoxically simultaneously ordered and disordered my narrative was the presence of the past. Another was the presence of the present in the past. Narratives are multi-layered. You cannot write only about yourself in the past, because the narrating you is in the present and you come from the past of which you write. You are part of both.

I found in those spaces that in-betweenness can be the effect of such structured spaces, not only the cause. Life cannot be contained by a narrative, other than momentarily. Story

expresses and commemorates a change in experience (Clandinin & Connolly, 2000). Because of this, writing about illness is a type of modern *ritual* of reintegration, even more than an *act* of reintegration. Narrative control is an illusion and narrative can be a highly ironic way of expressing yourself.

### 7.3 What the different parts of my story showed me

Writing is an experience in itself. I do not think we need to fear being trapped in an endless circle of interpretation (Denzin & Lincoln, 1998). When we write, we are not interpreting an experience so much as reinventing it by giving it structure and form. We are making something new and sometimes that something is ourselves.

Interestingly one of the patients in Russ et al.'s study only found acceptance of his lot when he could say out loud, "This is my life" and the dialysis technician could reflect that back to him, "Yes, this is your life" (2005, p. 321). The patient found that "sometimes the words come first" (p. 321). In writing about the shifts in identity and in narrative, sometimes the words do indeed come first. This was my experience in discovering littorality. Autoethnography can help a researcher to unlock this potential by creating the space for the words. It became a threshold of conceptual transformation (Meyer & Land, 2005), which allowed me to extend my understanding and my vocabulary and to cross some boundaries of my own.

In my dissertation the academic writing deconstructs the personal narratives and vice versa. Sometimes the personal and academic combine in a type of third space where something different can be born. Sometimes the tension between them creates a third space of uncertainty and multiple possibilities (Reed-Danahay, 1997; Richardson & St. Pierre, 2005). This can contain "troublesome knowledge" (Meyer & Land, 2005, p. 373), so that it can be safely considered. I treated each chapter differently because each concerned a different period in my life. However, this allowed each chapter to teach me something useful and unexpected. Sometimes these things concerned narrative. Sometimes they concerned me and my perceptions. Sometimes they concerned my medical condition.

#### 7.3.1 CKD and ESRD

My chapter on CKD and ESRD was the most difficult to write. At first I thought this was because the events I was writing about were from so long ago. Although they had taken so much of my childhood and adolescence, had been so much of each day's routine, they became curiously elusive when I began to write about them. Because so little is written on the childhood experience of CKD, I could find little stimulus in other academic work. I began to wonder why others had not written much about their own circumstances – youthfulness,

depression, physical disability, fear, grief or shame? This forced me to confront the truth about why I hadn't written about my condition growing up. I hadn't wanted to, for all of the reasons I attributed to other youngsters in the same circumstances.

Those ancient dreads began to surface in the journals I kept and the initial pieces I wrote that I found so unsatisfactory. My feelings about ESRD were no easier to deal with many years later. As an adult I was forced to see through older and more experienced eyes some grim realities about my life growing up with CKD and I was to notice the residue of this in every other part of my narrative, like the trail of a comet that has long ago burnt out.

I had originally hoped to achieve a compact, contained narrative of this period that would explain it all to me and provide me with closure. In my mind's eye this would be a typical illness narrative of organising chaos and restoring a damaged identity. To some extent it was, but I was shocked by the identity I saw – a vulnerable child living with a terminal condition, trying very hard to control it through following the prescriptions of medical science. From this I could see how the medical narrative had become the defining one in my life and I could also see how that narrative had silences, ambiguities and contradictions. My care providers tried not to alarm me, but they could not protect me forever. When my condition deteriorated, my belief in the medical version of events deteriorated too, leaving behind chaos, confusion and silence.

For instance, even in reconstructing that narrative, I did not tell (and still hesitate to do so because, even thirty years later, it makes me so anxious) of my doctor's recommendation that I stop school sport permanently when I was thirteen. School sport was compulsory. You could only stop it if you were seriously ill. I insisted on continuing with school sport throughout high school, not because I loved sport. I loathed school sport. Nor did I doggedly continue with so-called "games" lessons because I was courageous and filled with fighting spirit, but because I was terrified and preferred to live in denial about my condition. I could not bear being the only girl in the entire school who was so damaged that she was booked off sport permanently.

I was adrift without a narrative that even today I struggle to replace. I move away and towards an identity of vulnerability and terminal illness. The long liminal period between 8 months and 21 years had periods of littorality, an identity of its own distinct from life before and afterwards, with its own fluctuations and combinations of relative health and illness, but in retrospect was a waiting room for dialysis, transplantation or death.

### *7.3.2 Dialysis*

The chapter on dialysis presented a different type of perturbation. I believed my story about dialysis to be straightforward: it had saved my life and worked well for me. I thought that it



provided a cheerful counter-narrative to the gloomy tales one generally encounters in qualitative health research about dialysis. I wrote up a brisk version of my narrative and set about explaining it in more detail. Imagine my confusion when I back-tracked to extract some quotes from my narrative, only to find that I had two contradictory narratives and both were accurate depictions of my view of dialysis. I also came to see that once I included different snippets of information about the experience, the picture changed further. I moved away from and towards the experience. I identified with being the compliant patient, following my exercise and treatment routines, running as hard as I could from the encroaching vulnerability.

I also had to see that my predominant narrative was still medicalised. Internal colonisation is difficult to identify and to eradicate (Marquard, 1957). The medical narrative was easier to embrace here, because it made me feel as if I could control my fate, while towards the end of ESRD the medical narrative had left me feeling powerless. However, the price in toeing the medical narrative line was that I denied myself the chance of having a narrative of my own. Seeing for the first time the contradictoriness of my experience and the in-betweenness of my life on dialysis allowed me to start conceptualising the experience as much more emotionally complex than I had at first been able to see. The gaps, silences and omissions were sometimes the result of saving time in the telling, sometimes the result of not being able to face what had happened to me. I came to see that they were all part of the story. Was this liminality or littorality or both? Was I well or ill, or becoming something else entirely? Unlike during the years of my adolescence, I felt really well on dialysis, even though my kidneys had atrophied and I had a permanent abdominal catheter for which I used to perform four sterile bag-changes a day. For me dialysis was only ever a stop-gap (and hence liminal) and yet it gave me my first taste of what being well (or “well”) must be like. So perhaps it was littoral too.

And then there was the story I omitted about how I came to study part-time on dialysis. When I explained to the postgraduate supervisor that I was on dialysis and was waiting for a transplant whose date I could not predict, her response to me was to tell me that if I didn't think I could manage the course, perhaps I should not register for it. As with high school sport and for the same reasons of dread and denial, I registered anyway, but I did it part-time, so that if my kidney came up I would be able to have the transplant and still get my degree (which is exactly what happened). I needed to believe that I was well. This story of dialysis continues to be ruptured.

### *7.3.3 Transplantation and life post-transplant*

For the part about transplantation and the life afterwards I had initially wanted two chapters, so that I could clearly show the difference between the phases. I wrote up two chapters and realised belatedly that I was relapsing into the old, familiar medical narrative of transplantation

as a medical procedure, just as qualitative health research, sociology and anthropology often treat it, with the transplant recipient a passive recipient of another's organ, while the weighty philosophical and ethical battles rages on around one. I came to see that this was not my story.

At first I felt ashamed that I was bored and irritated by the dramatic narrative of transplantation, so much so that I did not explore it in my chapter about life after transplant. I felt drawn to a more traditional story of gratitude for my new lease on life, gratitude to my doctors, gratitude to my donor and his family. But I came to see this was not truly my narrative either. While I do indeed feel grateful, my role in both these traditional narratives is a passive one. I was more interested in a narrative in which I could play a more active role, where I could participate in making meaning out of the events in my own life. I committed the ultimate transgressive act when I dropped the chapter on transplantation from the story of organ failure, transplantation and life afterwards. But in so doing, I think, I left that liminal state forever. In rituals of liminality, the participants who are moving from one identity to another are passive (Kirschner, 2006).

This gave me a different perspective on my narrative. I came to see that it was very difficult to escape from these narrative forms, but that I had to, because my narrative was about dealing with liminality post-transplant, not fighting ethical battles around organ donation. In terms of understanding my post-transplant identity, this was the most empowering narrative event that has ever happened to me. From the beginning of my research my concern has been that much research on transplantation is really not about the qualitative experience of individuals' lives, but about larger abstract issues. In this type of research the individual's experience is lost. As important as policy and ethics are, as wonderful as medical science can be, illness is a human experience. It happens to individuals, not to systems. Its meaning is important to individuals, not to policies. And yet here I was doing the same thing.

The first timid draft of my own story began to emerge and it was as tenuous as my narrative of ESRD had been. I had never really told it before. Wellness was traumatic for me; I was completely unprepared for it. My identity was in ruins. I had no narrative to sustain me. All I had were some disconnected shocks visited on me by an environment of wellness in which I seemed not to belong. I came to see that I shifted between society's perceptions of well and ill, and that I had internalised this binary, unhelpful as it was in understanding my condition. I began to carve out a new and often painful narrative in which I came to see that I was not well or ill, but something else, as I had been on dialysis, but with some differences. I used the term "littoral" for this, because it was more helpful than merely being in-between one state and its opposite. This new narrative is not medical. It captures how I understand my identity now. It has been influenced by the successfulness of my transplant so far. It may well change in the

future. But for now I feel sustained by it and through it I can see my past in a different way: a journey through a dangerous and difficult terrain and one that I am still traversing. For the first time I see a possible future too. Littorality is something I can live with.

On 21 August 2011, for the first time in 20 years after having a transplant, I attended a memorial and dedication for organ donors. I did this because at last I could. And I was surrounded by people like me (although no one I spoke to had had their transplanted organs for more than a decade). “We are a family here,” one man told me. I have not had a family for a very long time.

#### **7.4 Learning to inhabit the littoral zone by using autoethnography**

Autoethnography is “dangerous” and invites perturbing self-questioning (Ellis, 2004, 2009). This is partly because in any reflexive activity one might be forced to confront things one would rather not. I was alarmed at my vulnerability because I had worked very hard my entire life to make myself as invulnerable as possible in my medical condition. Vulnerability for people like me can mean death. Some of the perturbation, however, is narrative in nature. Hollway and Jefferson (2000) show there is a link between ambiguous representations and people’s experience. Some experiences and one’s reactions to them are ambiguous by nature, but we find that difficult to accept and aim to resolve the tension if we can. If we can’t, we fear we may not have achieved closure. The desire for closure, for resolution, for ending tension can override our ability to use narrative to increase our understanding of certain experiences. From my own experience I can assure you that it is frightening telling your story of persistent in-betweenness. You might fear that you are living in-between worlds like that because you are doing something wrong, instead of seeing that this in-betweenness could be a rich and exciting experience.

For instance, I started as the Romantic writer, hoping to be heroic, unique and omniscient and to show the truth to the world (Denzin, 2009). I became the ethnographic writer, representative in some senses and exploratory. The writing became the experience as I negotiated my way from the peripheries to the centre and back again. I had a perception of myself that changed while writing my chapters. My identity was based in concealment and passing (Goffman, 1963/1990). When I started to become more like the person I actually was, I had to begin to stop becoming the person I thought I was. The past me I uncovered was different from the past me I remembered. In doing this I had to reconsider the (then) present me.

Everything remained dynamic in my research and this was a challenge. I managed to explore my own alterity to some extent and to discover a third space through *métissage* that allowed

me to articulate who I am in my various selves. But even now I have an urge to wrap it all up neatly and tie it with a bow of theory, so that it will be finished, even though life and its narratives go on.

#### *7.4.1 How autoethnographic was it?*

I still ask the eternal question: “Is it autoethnography yet?” Perhaps I have not changed as much as I thought. So I have decided, methodolatrously and against what I asserted in Chapter 3, to do a checklist. Criteria for assessment of autoethnography may vary somewhat (Ellis, 2000; Hudak, 2007; Richardson, 2000; Sparkes, 2000, 2001), but they usually cover the following:

- a. Has the work made a substantive contribution?
- b. Is it aesthetic?
- c. Is it reflexive?
- d. What type of impact has it had?
- e. Does it express lived experience?

Some of these criteria worry me, since they are somewhat subjective. They do, however, capture the more affective side of autoethnography and remind me of the importance of emotion in lived experience and in how we tell the story of that experience.

#### a) Has the work made a substantive contribution?

Whether or not my research has made a substantive contribution to research into the understanding lived experience of kidney disease is largely up to other researchers and people living with it to decide. For my own part, it has made a substantive contribution to my own understanding of living with kidney disease by revealing complexities and nuances of which I had previously been unaware, and by allowing me to confront, in a contained way, some of the experiences I had previously found too distressing to contemplate. This also allowed me to accept and assimilate my otherness and to understand that this was partly due to occupying a littoral space.

This was not merely therapy. In doing this I came to understand that some of my distress was caused by my own (mis)perceptions of my condition and by the narratives I persisted in telling myself. Some of these narratives were narratives I had acquired or inherited through my relations with family members, doctors, friends and associates. Writing this way allowed me to examine and contextualise my narratives within a particular postmodern framework and to reconstruct them from a new perspective that afforded me a more accurate view of my own

circumstances. My autoethnography is one of very few book-length discussions of kidney disease and, because my autoethnography is about my lived experiences of life-long kidney disease, it offers a unique perspective. Furthermore, it provides an alternative way of telling the story of kidney disease, where littorality is more flexible and dynamic and less stigmatised and less anxiety-producing than liminality.

b) Is it aesthetic?

There are too many different theories of aesthetic value for this criterion to be more than subjective. Perhaps I can frame this within a more limited range of whether or not I used emotional and sensory imagery to help achieve a thick description of the experience of kidney disease, and whether this thick description allowed me to interpret more meaning from the narrative than I would have, had it not been there. I found that allowing myself to write as freely as possible about the experiences and to remember that a reader may need to have the experiences described precisely permitted me to tell an emotional truth about them that I had sometimes even hidden from myself. In addition to this, writing this way allowed me to escape conforming completely to a medicalised narrative of facts and figures, which can only ever be part of the story. Of everything I learned during this research, I found this last point the most valuable and liberating.

c) Is it reflexive?

Nothing I wrote about would have been of any use had I not reflected constantly on the process of writing about it. The aesthetic part of my work could only achieve what it did because I reflected on what it meant. Making my story – this version of it anyway, because it will change the next time it is told – has compelled me to go back. I have had to reassemble memories. It has also made me go forward and to think about the future.

Reflecting in this way forced me to examine very closely my own perceptions and the ways in which I constructed my own narratives: my metaphors, my imagery, my influences. There is a lot of death in there. In Chapter 5, for instance, the first narrative fragment sets up a metaphor of Death as a cowboy. This metaphor is not unpacked and remains conceptually elusive, as one's own death is. Likewise a theme of myths involving death and life-in-death (Osiris, Persephone) runs through my narrative, dead-alive supernatural beings who occupy more than one realm exist in my story too (ghosts, vampires).

In addition to this, I reflected on the theoretical underpinning of my work and problematised the methodology. In Chapter 5 again, an academic introduction follows the cowboy story, taking a different and more rational tack and prepares you for the longer narrative about my experience of dialysis. In the academic discussion of the narrative I note how I was in two minds about my

story to the extent that I held two opposing versions of it in my mind. I also omitted large parts of it in the narrative, some of which I discuss in the academic section. The chapter ends with a different fragment of narrative that tells a different, and yet equally true to me, version of events. The chapters take different forms, depending on what needs to be said. Sometimes academic and narrative are blended, sometimes kept separate. I had to choose carefully how to do this in order to create certain types of effects.

Being constantly reflexive meant that I also had to deal with a surprising amount of emotion around writing about events that occurred very long ago. A perpetual battle raged in me between anger and rationality, between being swept along in a tumult of powerful emotions while having to step back and contemplate what this meant to me. Great sadness was more difficult for me to cope with and so was the ghostly remnant of great fear. The presence of the past and my death grip on some of it were issues I was not able to resolve. I live with vulnerability still, but in writing this way and having a narrative that is more my own, I have come to see that this is simply how my experience of kidney disease is. It is not right or wrong.

Ironically, being (self-) reflexive forced me to confront my anxiety about being narcissistic. After all, in some senses, the research is all about me. In confronting this I came to understand that, because it scared me, I had avoided focusing on my own story for much of my life and that this had consequences for me and my story. I also came to see that my story could have value for others by providing them with an alternative and more nuanced way of narrating and understanding the experience of transplantation and chronic illness.

d) What type of impact has it had?

The impact on me of writing autoethnographically has been profound. I do not think about kidney disease the same way as when I began. My view on organ transplantation is quite different too. This research has allowed me to embrace hidden parts of myself and to reclaim parts of my identity as an organ transplant recipient and as a person who does not represent the norm. I can even accept that I am in some senses disabled. Doing this has been a relief. But doing this was also a route to a more subtle understanding of how I tell my story and where I place myself in it. Postmodernism allowed me a more flexible way of managing ambiguity and led me to see that the binaries of well/ill and even the idea of liminality do not do justice to life post-transplant.

e) Does it express lived experience?

Does my research reflect the lived experience of kidney disease and the life post-transplant? It reflects my experience. It took a long time and much rewriting to reach the point where the narrative was more mine than other people's. Nonetheless I could not tell my whole story. I

had to choose what to include and what to leave out, because I had decided to write about a life-time's experiences. While I feel satisfied that I captured certain events quite clearly and that I chose to write about events for their significance and the way in which they fitted in with other events in the narrative(s), I am painfully aware of how much I have had to omit. I must conclude that what I have told reflects some of the experience of kidney disease and organ transplantation.

#### *7.4.2 Working with the methodological challenges*

Through reflexivity I was able to remain aware of my on-going pull towards traditional methodologies. I had to remind myself constantly that while I was working with meta-issues, I was not looking for generalisability or statistical verification of my findings. However, the tug towards empirically-based methodologies was powerful. I also had to remind myself that my narratives weren't data, but a means of developing and structuring knowledge. This left me feeling off-kilter during my research, constantly doubting the worthiness of my work. As unpleasant as this was, it was beneficial, because it kept me critical of my findings and methodology. The uncertainty that I experienced was itself a type of littoral space, where I oscillated between epistemological complacency and serious doubt. Not only was this performative and postmodern, allowing me to question power and perspective, including my own, but it allowed me to develop my ideas further.

Representing the Other was a more troublesome challenge. This challenge would show up unexpectedly where I had medicalised parts of my earlier narrative versions. It emerged when I slipped back into traditional ways of using narratives as data. I experienced it as the greatest challenge when writing about myself as a child. Looking back to those times as an adult was a sobering experience and I found it extremely difficult to avoid writing about myself then as a pitiable victim. I had never been able to afford to see how devastating CKD and ESRD had been to me or to my family, nor could I afford to see how powerless I had been as a child in those circumstances. I found myself attempting to redress this by writing about ways in which I had gained control of my medical situation (for example, being responsible for my own medication from the age of 9). I do not think I completely avoided othering myself, but I do think that I managed to move between othering and not othering myself, and that this in itself may show a more nuanced picture of how I perceive my situation.

This was a type of *métissage*, because, by combining these different points of view and ways of telling, it liberated me from the place from which I began to speak (Buzard, 1999) by providing me with a more empowering and sophisticated alternative story. My focus changed from anger and victimhood, pity and fear and I began to speak of other things, such as finding more subtle ways of defining my position. I may still be trapped from time to time in certain



discourses, ontologies and epistemologies, but being aware of this propensity has allowed me to reflect on and change my position. I now think, along with Reed-Danahay (1997), that we should not aim for a freedom we may not be able to achieve, but we should rather keep moving and not let any identity clothe us for too long, nor to become too much at home in one or other position. In this way I experienced my research as truly autoethnographic.

While autoethnography has allowed me to inhabit the messiness and contingency of life to an extent, the urge to order and structure is impossible to resist when writing a narrative, because the very act of doing so is a way of ordering events to gain meaning. This was an on-going tension, especially pronounced when I had to choose what to put in and what to leave out. Again reflexivity allowed me to make sense of these choices and, paradoxically, to acknowledge the imperfect nature of my work.

This tension emerged also in the dialectics of the personal and the academic, and of rationalism and rhetoric, theory and practice. I had to rework parts of my dissertation to achieve a better balance between anger (particularly) and rationality. Journaling helped me with this, especially when reading research that filled me with so much fury that it prevented me from being objective. This forced me to examine why I felt as much anger as I did towards some researchers. I had to conclude that it was usually because they were outside the issue they were examining, were not involved with the everyday lives and needs of the people they were studying, and could leave any time they wanted, while I could not. Two particular instances are those of Fox and Swazey (1992) and Scheper-Hughes (2007).

Occasionally I realised that I felt contempt for those whose conditions were not as serious as mine, but who were, nonetheless, writing about them autoethnographically and were deeply affected by them (Ettorre, 2005; Oakley, 2009). I had to remind myself constantly that these researchers had every right to feel affected by their circumstances and to conceptualise them within their chosen theoretical frameworks. Their work had academic merit. At the heart of this and of my anger for these researchers lay a melancholy truth: I saw myself as trapped and victimised by my condition and had conferred upon myself as consolation an heroic mantle of having earned my right to speak about serious issues. This mantle was extremely difficult to remove.

In holding onto this idea that I was more injured and therefore more deserving, I ran the risk of polarising not only the identities of these researchers and of othering them, but also of polarising my identity as ill person and my identity as researcher. This can prevent one from seeing what one has in common with other researchers and with other circumstances. It can also prevent one realising the implications of multiple intersecting identities, one's own and

others'. Although one doesn't want to generalise, it is possible to abstract if one keeps a balance between indignation or outrage and intellectual inquiry. As I came to see, we are all subjects, all situated somewhere in our own and others' narratives (Richards, 2008). One type of inquiry does not negate others, nor does one method of inquiry. This was a challenge to remember as I became more deeply immersed in my own work.

I came to wonder if autoethnography might not be a way of countering disappearance and ritually ending a liminal state, instead of perpetuating one. Accepting that one inhabits some type of borderland (Pratt, 1992), more specifically, a changeable littoral zone, instead of moving through porous borders between one state and the other might be a more helpful way of seeing one's chronic condition. Where did I position myself? I had to accept that I did not always live in a borderland, but sometimes travelled between lands, not really a citizen of any that I temporarily inhabited. I was both researcher and researchee. There is no borderland there, only dual citizenship.

In the case of inhabiting the kingdom of the well and the kingdom of the ill post-transplant, however, it becomes more complex and this is what I spent considerable time writing about: you can be well or ill or neither or both, and you will be all of these at different times and some of them at the same time. But that does not necessarily grant you a country of your own. Autoethnography as *métissage* can create a dynamic third space, a littoral zone, for capturing those ideas, expressing them or understanding them, even if it is only a space that is changeable and impermanent. In this dynamic littoral zone I was able to explore my feelings through writing about them and by so doing I was able to move beyond merely representing them and objectifying them.

I may write in a certain confident (academic) tone, but my intention is that this should not belie my inherent uncertainty. I do not intend that my identity become fixed or that my ideas become merely ideas. For them to be of value to me, they must be in some way embodied and debated. They must argue with you the reader as they must remain unsettled in my own mind. That way they – and I – remain alive.

## **7.5 Postmodernity and narratives of chronic illness**

The insider's view of life post-transplant has not been much explored in literature and especially not in book-length narratives. Life long after transplant has received very little attention, as has childhood experience of chronic kidney disease. Because of the seriousness of kidney disease and the paucity of narratives, I have found much space for exploration of the

narratives one might tell, but I have also found how to tell them rather more complex than might at first have been expected and hence I resorted to using a postmodern paradigm.

Postmodernity can be a useful paradigm in qualitative health research, especially when working through the messiness and contingency of everyday life in chronic illness. I have found that moving away from the urge to obtain closure or neatness, and moving towards ambiguity, ambivalence and contradiction can allow one to claim a voice for oneself and a way of expressing some of the complexity of living with a chronic condition.

The blurring of genres and roles that occurs when pursuing a postmodern view of research can go part of the way towards redressing power imbalances or at least to drawing attention to them. In this way attention can be paid to the positioning and identity of the Other and even perhaps to how the Other positions and identifies herself (Lionnet, 1995). Doing this can allow the centre to shift and those on the peripheries to move inward. This can be useful to take into account when including patients' voices in research.

Using a postmodern paradigm is one way of creating a space in which to consider narrative more closely and to problematise the ways in which it functions in writing about chronic illness. This is because it allows one greater awareness of the text and of one's own role as one tells a story and mediates experience. My use of autoethnography allowed me to problematise the outsider/insider perspectives and to re-evaluate my understanding of my own positioning in this regard. I also had to consider the curious position of writing an illness narrative about not being ill. Autoethnography is a type of academic subjunctive that can capture the subjunctive experience (Good & Good, 1994) of chronic illness.

Many illness narratives take the form of a quest or restitution. Some are chaos narratives, but this tends to leave people longing for order and closure. At first I tried to flee from these forms, but I came to see that I could not. Instead I found that the forms I used changed during the narrative. Because of my autoethnographic approach I was aware of this and needed to consider its implications for my narrative.

This also allowed me to reconsider the typical transplant narrative of a disruptive illness exorcised by a miraculous gift, or the narrative of great loss and a permanent medical condition delivering hidden gains. Both of these types are essentially comic plot narratives. The pull to write this way is strong and the imperative to do so seems almost moral. But within the intellectual framework that autoethnography gave me I was able to explore the complexities, tensions and uncertainties that my narrative showed.

Although the doctor-patient relationship has changed over the last few decades, people living with chronic conditions can find themselves caught up in a medicalised version of their lives. Possibly a reason I have never been able to write my story until now is that my prognosis, the story plotted out for me by a doctor about buying another decade of life, haunted me. It left me feeling as if I was waiting for the end and that it was nigh. I hoped that it would not be true. Also, the doctor's plotting out of my story, no doubt to speak the truth and bring comfort, made me feel that it had already been told. But it had not been told by me. I shall have to tell my story many times, I think, to make it real.

As for many people living with chronic conditions, my medical history is a large part of who I am. Through autoethnography and an exploration of illness narratives I see that now. It has been part of my life on every level since I was 8 months old. Kidney failure didn't change my life. It has been in my life always, like a secret sharer. It has helped create my identity, my choices, who I am. And I want people to know who I am.

## **7.6 Unanswered questions, unresolved issues and future research**

My research is only a small inroad into the lived experience of CKD, transplantation and the life afterwards. The few snapshots I managed to gather give only a glimpse of what is there to study. Much useful work can be done on the experience of dialysis and there is a lot of scope for work on the experience of transplants that reject. Likewise much can be done on the childhood experience of CKD. As time goes on and if I am fortunate enough to keep my kidney, work could be done on the experience of transplantation 40 years down the line.

A number of other issues can be explored. One is the roles of narcissism and anxiety in creating narratives of chronic illness. This might be pursued through a focus on narcissistic wounding, shame and bereavement or vulnerability and an urge to force closure.

Another topic to investigate further is the taboo narrative. What becomes of stories that go against what society dictates, for instance, how a dysfunctional family affects the choices and the narratives of a person with a chronic medical condition (and vice versa)? What types of taboo narratives does one find? Few families are fully functional and a lot of resentment, anger and feeling burdened by others' problems seethes beneath our socially acceptable facades, even when a family member is dying.

The tension between self and other, specific and general is difficult to sustain in narrative. In the end, if one produces a narrative of one's own life for an audience, it needs to mean something to others and to be useful to them. They must either be able to relate to it (i.e. as

patients) or to use it (as academics). This way that this is achieved may usefully be further explored in research about the experience of chronic illness.

Further understanding of criteria needed for research that blurs the boundaries of the personal and the academic could continue with specific reference to the use of autoethnography in chronic illness. It is possible that chronic illness autoethnography may need its own criteria.

There are times to read stories and times not to read them. These times vary from person to person. Reading a story of uncertainty might help or harm a person with a chronic illness. They might need to master challenges of day-to-day living and the new realities of their condition. They might need the little certainty they can find before they learn to live with uncertainty, whether the uncertainty of continued relative health or the uncertainty of a miraculous, but undependable cure. This could bear further research. I contend that to some extent we create stories we require at the times we need them. They are true for us then, but may change as our needs develop.

One's medical history is always part of one's life, even if one has always been robustly well. In that case one's "lack" of medical experience informs one's life and attitude to sickness and health. One's view of "normal" is what one mostly lives. A study I would like to see is how obscene good health distorts one's body image and gives an unrealistic perception of what life is really about, thereby causing one to respond adversely to people from whom one is different to to experience illness as disruptive instead of merely part of life. Difference, like beauty, is after all in the eye of the beholder.

## **7.7 Some concluding remarks**

I have recently discovered on the internet that HUS can be caused by eating salad that has been washed in water contaminated by e-coli or that one might come into contact with it if one interacts with feral swine. I feel that neither of these options really helps me to establish how I encountered it. I did not eat salad at the age of 8 months and I certainly did not play with feral swine. So, as always, I am not closer to establishing how I did encounter it. I do not feel a sense of urgency about finding out. Amongst the people I know, including all the transplantees, I am the only one to have suffered from it. After all these years I doubt I will encounter it again.

My illness, like God's agency, is only known by its effects. Everything that happened to me afterwards was as a result of an illness that had long burnt itself out of my system. I am indelibly imprinted by it almost to the extent that it is who I am, as if it were a third parent contributing to my gene pool.

As for Glissant's "perpetual becoming" (2002, p. 292), I have been "becoming" for my entire life and yet I still am here (so to speak). I have realised in telling my story that I do not any longer truly experience liminality and Santiago's "space between" (Pratt, 2002, p. 32). When I did, it was disquieting because I did not have a narrative for it. Now I occupy a littoral space. I may have inhabited it for a very long time without knowing it, because I did not have a story for it. I also realise, after spending some time trying to find "the" story of my life, that my story keeps changing. It is itself always in transition. It shall continue to become. I cannot and should not try to fix it. A story is a bridge from here to there. It can give the illusion of being eternal, but it is not. My narrative is a palimpsest of other stories and other identities that affect the present in my long road through chronic illness. Things change and return. Identities oscillate. We must cope with ambiguity and even learn to embrace it.

Now that I understand this better, I am not alarmed by it. It no longer perturbs me. For years I did not have a story, but instead a mosaic of story fragments that were my own and other people's, because I was afraid to write my own narrative. The liminality scared me and I did not think I could justify my experiences that seemed so distant from the other stories I encountered. Maybe now I can begin (again) to tell my story, knowing that my identity is littoral and postmodern. I am not a blend of well and ill, or a splicing together of different types of narratives. My identity is a type of métissage. I am no longer trapped in the place from which I began to speak. I have dismantled the narratives that colonised my life for so long. In the meantime, I shall pause this text and leave it here.

## 7.8 One last story: The fate of numbers

*Patient 548820 does not exist anymore, except as a file somewhere in a neon-lit basement. I left the Johannesburg General Hospital in 1995 and I plan never to return. In my black A4 notebook, where I have religiously charted my blood pressure, blood results and allergies since the early nineties, I wrote under the last set of blood results from the Gen, "Never coming back!!"*

*When I moved to Groote Schuur I got a new number. I was no longer 548820. Like my original identity, my new one was printed on a white sticker, but this time, instead of being stuck on an endless succession of forms, prescriptions and requests for blood tests, it was stuck to a green card on which I was supposed to write the dates of my appointments. I did it for the first three appointments in the first year and then I stopped. I know I still have the card somewhere (one tends to keep one's identity documents safe), but significantly I don't know where it is. I don't know my "new" hospital number either. I have had it for 15 years.*

*I moved a couple of years ago to a private specialist, but I didn't close my file at Grootte Schuur and the nursing sisters suggested that my specialist update them each year so they can update my file. I do not expect trouble, but just in case. Just in case I am too poor to afford private treatment. Just in case I develop complications. Just in case my transplant fails. Just in case I need to use my other passport again or I am deported when the authorities realise my papers aren't valid and I'm not really "one of us". My specialist has a number for me too and a file. His is a shorter number: RIC0003. He never calls me by it. 938 only exists in the dusty filing cabinets of my heart. And in a note on the cover of my black notebook, written in by my mother, underneath my General Hospital sticker.*

*The story of 548820 resides in me, but is not all of me. I am also partly 938 now. And I am, on occasion, RIC0003. I am not sure if I should add or multiply these numbers. If they are added, multiplied or laid together end-to-end, they do make an impressive total. I am not sure I can live up to it (or remember it). And yet I suspect that the sum is greater than the parts.*

*And yet all of us will always exist. 548820 has lived amongst these pages and every time they are opened she breathes again. I have written about her and contained her. But I have also almost managed to set her free. She has lived so long that she almost has an identity of her own. Even if she can't manage without me, I am half convinced that I cannot manage without her, especially when I need to remember to take my medication, keep to some sort of diet and attend to doctors' visits. She is as much a part of me as 938. She is my secret sharer too. And when things go wrong or I find myself back in a large hospital, we change places.*

*I haven't worn or renewed my Medic Alert bracelet since it fell off my arm the day I didn't get the Oxford scholarship. I have it still. It exists, with its broken chain in a wooden box on a high window sill in my bedroom. Its red lettering has almost been effaced, but you can still read its number: 327959\*. My number is so short and so old it needs an asterisk to complete it. It has become a liminal thing, isolated from polite jewellery, its traces of identity besmirched. But it will return. They always do.*

*You see, I am considering wearing it again – or having a new one made. Recently I fell seriously ill in Canada. I was so far away from home and so sick I could almost not speak for myself. All I managed to croak deliriously when the ambulance men questioned me about my health was "kidney transplant, kidney transplant". I wished I had worn my Medic Alert bracelet then. I still have my kidney. And I keep forgetting to follow up on the bracelet.*



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